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Form 990

Return of Organization Exempt From Income Tax

OMB No 1545-0047

2019

Open to Public Inspection

Under section 501(c), 527, or 4947(a)(1) of the Internal Revenue Code (except private foundations)

Do not enter social security numbers on this form as it may be made public

Go to www.irs.gov/Form990 for instructions and the latest information.

A For the 2019 calendar year, or tax year beginning 01-01-2019 , and ending 12-31-2019

B Check if applicable

Address change

Name change

Initial return

Final return/terminated

Amended return

Application pending

C Name of organization

NATIONAL ORGANIZATION FOR RARE DISORDERS INC

Doing business as

Number and street (or P O box if mail is not delivered to street address) Room/suite

1900 CROWN COLONY DR 3RD FL NO

City or town, state or province, country, and ZIP or foreign postal code

QUINCY, MA 02169

F Name and address of principal officer

VINCENT J MURPHY JR

1900 CROWN COLONY DR 3RD FL NO 310

QUINCY, MA 02169

H(a) Is this a group return for subordinates?

subordinates?

Yes No

H(b) Are all subordinates included?

Yes No

If "No," attach a list (see instructions)

H(c) Group exemption number

I Tax-exempt status

501(c)(3)

501(c) () (insert no)

4947(a)(1) or

527

J Website: WWW RARE DISEASES ORG

K Form of organization

Corporation

Trust

Association

Other

L Year of formation 1983

M State of legal domicile NY

Part I Summary

Activities & Governance

1 Briefly describe the organization's mission or most significant activities

NORD STRIVES TO IMPROVE THE LIVES OF THOSE WITH RARE DISEASES THROUGH ASSISTANCE PROGRAMS, EDUCATION, ADVOCACY AND RESEARCH

2 Check this box if the organization discontinued its operations or disposed of more than 25% of its net assets

3 Number of voting members of the governing body (Part VI, line 1a)

4 Number of independent voting members of the governing body (Part VI, line 1b)

5 Total number of individuals employed in calendar year 2019 (Part V, line 2a)

6 Total number of volunteers (estimate if necessary)

7a Total unrelated business revenue from Part VIII, column (C), line 12

7b Net unrelated business taxable income from Form 990-T, line 39

Revenue

8 Contributions and grants (Part VIII, line 1h)

9 Program service revenue (Part VIII, line 2g)

10 Investment income (Part VIII, column (A), lines 3, 4, and 7d)

11 Other revenue (Part VIII, column (A), lines 5, 6d, 8c, 9c, 10c, and 11e)

12 Total revenue—add lines 8 through 11 (must equal Part VIII, column (A), line 12)

Expenses

13 Grants and similar amounts paid (Part IX, column (A), lines 1–3)

14 Benefits paid to or for members (Part IX, column (A), line 4)

15 Salaries, other compensation, employee benefits (Part IX, column (A), lines 5–10)

16a Professional fundraising fees (Part IX, column (A), line 11e)

b Total fundraising expenses (Part IX, column (D), line 25)

17 Other expenses (Part IX, column (A), lines 11a–11d, 11f–24e)

18 Total expenses Add lines 13–17 (must equal Part IX, column (A), line 25)

19 Revenue less expenses Subtract line 18 from line 12

Net Assets or Fund Balances

20 Total assets (Part X, line 16)

21 Total liabilities (Part X, line 26)

22 Net assets or fund balances Subtract line 21 from line 20

Prior Year

Current Year

Beginning of Current Year

End of Year

Part II Signature Block

Under penalties of perjury, I declare that I have examined this return, including accompanying schedules and statements, and to the best of my knowledge and belief, it is true, correct, and complete Declaration of preparer (other than officer) is based on all information of which preparer has any knowledge

Sign Here

Signature of officer

VINCENT J MURPHY JR VICE PRESIDENT OF FINANCE

Type or print name and title

2020-07-21

Date

Paid Preparer Use Only

Print/Type preparer's name

Preparer's signature

Date 2020-07-06

Check if self-employed

PTIN P01645518

Firm's name AAFCPAS INC

Firm's EIN 04-2571780

Firm's address 50 WASHINGTON STREET

Phone no (508) 366-9100

WESTBOROUGH, MA 01581

May the IRS discuss this return with the preparer shown above? (see instructions)

Yes No

For Paperwork Reduction Act Notice, see the separate instructions.

Cat No 11282Y

Form 990 (2019)

Part III Statement of Program Service AccomplishmentsCheck if Schedule O contains a response or note to any line in this Part III ☒**1** Briefly describe the organization's mission

NORD LEADS THE FIGHT TO IMPROVE THE LIVES OF PEOPLE AFFECTED BY RARE DISEASES THROUGH EDUCATION, PATIENT ASSISTANCE PROGRAMS, ADVOCACY, AND BY PROMOTING RESEARCH

2 Did the organization undertake any significant program services during the year which were not listed on the prior Form 990 or 990-EZ? ☐ Yes ☒ No

If "Yes," describe these new services on Schedule O

3 Did the organization cease conducting, or make significant changes in how it conducts, any program services? ☐ Yes ☒ No

If "Yes," describe these changes on Schedule O

4 Describe the organization's program service accomplishments for each of its three largest program services, as measured by expenses. Section 501(c)(3) and 501(c)(4) organizations are required to report the amount of grants and allocations to others, the total expenses, and revenue, if any, for each program service reported

4a	(Code)	(Expenses \$	32,683,732	including grants of \$	30,812,906)	(Revenue \$	5,758,863)
See Additional Data							

4b	(Code)	(Expenses \$	1,208,255	including grants of \$	)	(Revenue \$	111,541)
See Additional Data							

4c	(Code)	(Expenses \$	1,553,178	including grants of \$	535,130)	(Revenue \$	105,187)
See Additional Data							

See Additional Data Table

4d	Other program services (Describe in Schedule O)					
	(Expenses \$	1,931,633	including grants of \$	)	(Revenue \$	2,416,919)

4e	Total program service expenses ▶	37,376,798
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Part IV Checklist of Required Schedules

	Yes	No
1 Is the organization described in section 501(c)(3) or 4947(a)(1) (other than a private foundation)? If "Yes," complete Schedule A 	1 Yes	
2 Is the organization required to complete Schedule B, Schedule of Contributors (see instructions)? 	2 Yes	
3 Did the organization engage in direct or indirect political campaign activities on behalf of or in opposition to candidates for public office? If "Yes," complete Schedule C, Part I 	3	No
4 Section 501(c)(3) organizations. Did the organization engage in lobbying activities, or have a section 501(h) election in effect during the tax year? If "Yes," complete Schedule C, Part II 	4 Yes	
5 Is the organization a section 501(c)(4), 501(c)(5), or 501(c)(6) organization that receives membership dues, assessments, or similar amounts as defined in Revenue Procedure 98-19? If "Yes," complete Schedule C, Part III 	5	No
6 Did the organization maintain any donor advised funds or any similar funds or accounts for which donors have the right to provide advice on the distribution or investment of amounts in such funds or accounts? If "Yes," complete Schedule D, Part I 	6	No
7 Did the organization receive or hold a conservation easement, including easements to preserve open space, the environment, historic land areas, or historic structures? If "Yes," complete Schedule D, Part II 	7	No
8 Did the organization maintain collections of works of art, historical treasures, or other similar assets? If "Yes," complete Schedule D, Part III 	8	No
9 Did the organization report an amount in Part X, line 21 for escrow or custodial account liability, serve as a custodian for amounts not listed in Part X, or provide credit counseling, debt management, credit repair, or debt negotiation services? If "Yes," complete Schedule D, Part IV 	9	No
10 Did the organization, directly or through a related organization, hold assets in temporarily restricted endowments, permanent endowments, or quasi endowments? If "Yes," complete Schedule D, Part V	10	No
11 If the organization's answer to any of the following questions is "Yes," then complete Schedule D, Parts VI, VII, VIII, IX, or X as applicable		
a Did the organization report an amount for land, buildings, and equipment in Part X, line 10? If "Yes," complete Schedule D, Part VI 	11a Yes	
b Did the organization report an amount for investments—other securities in Part X, line 12 that is 5% or more of its total assets reported in Part X, line 16? If "Yes," complete Schedule D, Part VII 	11b	No
c Did the organization report an amount for investments—program related in Part X, line 13 that is 5% or more of its total assets reported in Part X, line 16? If "Yes," complete Schedule D, Part VIII 	11c	No
d Did the organization report an amount for other assets in Part X, line 15 that is 5% or more of its total assets reported in Part X, line 16? If "Yes," complete Schedule D, Part IX 	11d	No
e Did the organization report an amount for other liabilities in Part X, line 25? If "Yes," complete Schedule D, Part X 	11e Yes	
f Did the organization's separate or consolidated financial statements for the tax year include a footnote that addresses the organization's liability for uncertain tax positions under FIN 48 (ASC 740)? If "Yes," complete Schedule D, Part X 	11f Yes	
12a Did the organization obtain separate, independent audited financial statements for the tax year? If "Yes," complete Schedule D, Parts XI and XII 	12a Yes	
b Was the organization included in consolidated, independent audited financial statements for the tax year? If "Yes," and if the organization answered "No" to line 12a, then completing Schedule D, Parts XI and XII is optional 	12b	No
13 Is the organization a school described in section 170(b)(1)(A)(ii)? If "Yes," complete Schedule E	13	No
14a Did the organization maintain an office, employees, or agents outside of the United States?	14a	No
b Did the organization have aggregate revenues or expenses of more than \$10,000 from grantmaking, fundraising, business, investment, and program service activities outside the United States, or aggregate foreign investments valued at \$100,000 or more? If "Yes," complete Schedule F, Parts I and IV 	14b	No
15 Did the organization report on Part IX, column (A), line 3, more than \$5,000 of grants or other assistance to or for any foreign organization? If "Yes," complete Schedule F, Parts II and IV 	15 Yes	
16 Did the organization report on Part IX, column (A), line 3, more than \$5,000 of aggregate grants or other assistance to or for foreign individuals? If "Yes," complete Schedule F, Parts III and IV 	16	No
17 Did the organization report a total of more than \$15,000 of expenses for professional fundraising services on Part IX, column (A), lines 6 and 11e? If "Yes," complete Schedule G, Part I (see instructions)	17	No
18 Did the organization report more than \$15,000 total of fundraising event gross income and contributions on Part VIII, lines 1c and 8a? If "Yes," complete Schedule G, Part II 	18 Yes	
19 Did the organization report more than \$15,000 of gross income from gaming activities on Part VIII, line 9a? If "Yes," complete Schedule G, Part III 	19	No
20a Did the organization operate one or more hospital facilities? If "Yes," complete Schedule H	20a	No
b If "Yes" to line 20a, did the organization attach a copy of its audited financial statements to this return?	20b	
21 Did the organization report more than \$5,000 of grants or other assistance to any domestic organization or domestic government on Part IX, column (A), line 1? If "Yes," complete Schedule I, Parts I and II 	21 Yes	

Part IV Checklist of Required Schedules (continued)

		Yes	No	
22	Did the organization report more than \$5,000 of grants or other assistance to or for domestic individuals on Part IX, column (A), line 2? If "Yes," complete Schedule I, Parts I and III	22	Yes	
23	Did the organization answer "Yes" to Part VII, Section A, line 3, 4, or 5 about compensation of the organization's current and former officers, directors, trustees, key employees, and highest compensated employees? If "Yes," complete Schedule J	23	Yes	
24a	Did the organization have a tax-exempt bond issue with an outstanding principal amount of more than \$100,000 as of the last day of the year, that was issued after December 31, 2002? If "Yes," answer lines 24b through 24d and complete Schedule K. If "No," go to line 25a	24a		No
b	Did the organization invest any proceeds of tax-exempt bonds beyond a temporary period exception?	24b		
c	Did the organization maintain an escrow account other than a refunding escrow at any time during the year to defease any tax-exempt bonds?	24c		
d	Did the organization act as an "on behalf of" issuer for bonds outstanding at any time during the year?	24d		
25a	Section 501(c)(3), 501(c)(4), and 501(c)(29) organizations. Did the organization engage in an excess benefit transaction with a disqualified person during the year? If "Yes," complete Schedule L, Part I	25a		No
b	Is the organization aware that it engaged in an excess benefit transaction with a disqualified person in a prior year, and that the transaction has not been reported on any of the organization's prior Forms 990 or 990-EZ? If "Yes," complete Schedule L, Part I	25b		No
26	Did the organization report any amount on Part X, line 5 or 22 for receivables from or payables to any current or former officer, director, trustee, key employee, creator or founder, substantial contributor, or 35% controlled entity or family member of any of these persons? If "Yes," complete Schedule L, Part II	26		No
27	Did the organization provide a grant or other assistance to any current or former officer, director, trustee, key employee, creator or founder, substantial contributor, or employee thereof, a grant selection committee member, or to a 35% controlled entity (including an employee thereof) or family member of any of these persons? If "Yes," complete Schedule L, Part III	27		No
28	Was the organization a party to a business transaction with one of the following parties (see Schedule L, Part IV instructions for applicable filing thresholds, conditions, and exceptions)			
a	A current or former officer, director, trustee, key employee, creator or founder, or substantial contributor? If "Yes," complete Schedule L, Part IV	28a		No
b	A family member of any individual described in line 28a? If "Yes," complete Schedule L, Part IV	28b		No
c	A 35% controlled entity of one or more individuals and/or organizations described in lines 28a or 28b? If "Yes," complete Schedule L, Part IV	28c		No
29	Did the organization receive more than \$25,000 in non-cash contributions? If "Yes," complete Schedule M	29	Yes	
30	Did the organization receive contributions of art, historical treasures, or other similar assets, or qualified conservation contributions? If "Yes," complete Schedule M	30		No
31	Did the organization liquidate, terminate, or dissolve and cease operations? If "Yes," complete Schedule N, Part I	31		No
32	Did the organization sell, exchange, dispose of, or transfer more than 25% of its net assets? If "Yes," complete Schedule N, Part II	32		No
33	Did the organization own 100% of an entity disregarded as separate from the organization under Regulations sections 301.7701-2 and 301.7701-3? If "Yes," complete Schedule R, Part I	33		No
34	Was the organization related to any tax-exempt or taxable entity? If "Yes," complete Schedule R, Part II, III, or IV, and Part V, line 1	34		No
35a	Did the organization have a controlled entity within the meaning of section 512(b)(13)?	35a		No
b	If "Yes" to line 35a, did the organization receive any payment from or engage in any transaction with a controlled entity within the meaning of section 512(b)(13)? If "Yes," complete Schedule R, Part V, line 2	35b		
36	Section 501(c)(3) organizations. Did the organization make any transfers to an exempt non-charitable related organization? If "Yes," complete Schedule R, Part V, line 2	36		No
37	Did the organization conduct more than 5% of its activities through an entity that is not a related organization and that is treated as a partnership for federal income tax purposes? If "Yes," complete Schedule R, Part VI	37		No
38	Did the organization complete Schedule O and provide explanations in Schedule O for Part VI, lines 11b and 19? Note. All Form 990 filers are required to complete Schedule O	38	Yes	

Part V Statements Regarding Other IRS Filings and Tax ComplianceCheck if Schedule O contains a response or note to any line in this Part V ☐

		Yes	No	
1a	Enter the number reported in Box 3 of Form 1096. Enter -0- if not applicable	1a	27	
b	Enter the number of Forms W-2G included in line 1a. Enter -0- if not applicable	1b	0	
c	Did the organization comply with backup withholding rules for reportable payments to vendors and reportable gaming (gambling) winnings to prize winners?	1c	Yes	

Part V Statements Regarding Other IRS Filings and Tax Compliance (continued)

2a Enter the number of employees reported on Form W-3, Transmittal of Wage and Tax Statements, filed for the calendar year ending with or within the year covered by this return	2a 91			
b If at least one is reported on line 2a, did the organization file all required federal employment tax returns? Note. If the sum of lines 1a and 2a is greater than 250, you may be required to e-file (see instructions)			2b	Yes
3a Did the organization have unrelated business gross income of \$1,000 or more during the year? . . .			3a	No
b If "Yes," has it filed a Form 990-T for this year? If "No" to line 3b, provide an explanation in Schedule O . . .			3b	
4a At any time during the calendar year, did the organization have an interest in, or a signature or other authority over, a financial account in a foreign country (such as a bank account, securities account, or other financial account)? . . .			4a	No
b If "Yes," enter the name of the foreign country See instructions for filing requirements for FinCEN Form 114, Report of Foreign Bank and Financial Accounts (FBAR)				
5a Was the organization a party to a prohibited tax shelter transaction at any time during the tax year? . . .			5a	No
b Did any taxable party notify the organization that it was or is a party to a prohibited tax shelter transaction?			5b	No
c If "Yes," to line 5a or 5b, did the organization file Form 8886-T?			5c	
6a Does the organization have annual gross receipts that are normally greater than \$100,000, and did the organization solicit any contributions that were not tax deductible as charitable contributions? . . .			6a	No
b If "Yes," did the organization include with every solicitation an express statement that such contributions or gifts were not tax deductible?			6b	
7 Organizations that may receive deductible contributions under section 170(c).				
a Did the organization receive a payment in excess of \$75 made partly as a contribution and partly for goods and services provided to the payor?			7a	Yes
b If "Yes," did the organization notify the donor of the value of the goods or services provided?			7b	Yes
c Did the organization sell, exchange, or otherwise dispose of tangible personal property for which it was required to file Form 8282?			7c	No
d If "Yes," indicate the number of Forms 8282 filed during the year	7d			
e Did the organization receive any funds, directly or indirectly, to pay premiums on a personal benefit contract?			7e	No
f Did the organization, during the year, pay premiums, directly or indirectly, on a personal benefit contract? . . .			7f	No
g If the organization received a contribution of qualified intellectual property, did the organization file Form 8899 as required?			7g	
h If the organization received a contribution of cars, boats, airplanes, or other vehicles, did the organization file a Form 1098-C?			7h	
8 Sponsoring organizations maintaining donor advised funds. Did a donor advised fund maintained by the sponsoring organization have excess business holdings at any time during the year?			8	
9 Sponsoring organizations maintaining donor advised funds.				
a Did the sponsoring organization make any taxable distributions under section 4966?			9a	
b Did the sponsoring organization make a distribution to a donor, donor advisor, or related person? . . .			9b	
10 Section 501(c)(7) organizations. Enter				
a Initiation fees and capital contributions included on Part VIII, line 12	10a			
b Gross receipts, included on Form 990, Part VIII, line 12, for public use of club facilities	10b			
11 Section 501(c)(12) organizations. Enter				
a Gross income from members or shareholders	11a			
b Gross income from other sources (Do not net amounts due or paid to other sources against amounts due or received from them)	11b			
12a Section 4947(a)(1) non-exempt charitable trusts. Is the organization filing Form 990 in lieu of Form 1041?			12a	
b If "Yes," enter the amount of tax-exempt interest received or accrued during the year	12b			
13 Section 501(c)(29) qualified nonprofit health insurance issuers.				
a Is the organization licensed to issue qualified health plans in more than one state? Note. See the instructions for additional information the organization must report on Schedule O			13a	
b Enter the amount of reserves the organization is required to maintain by the states in which the organization is licensed to issue qualified health plans	13b			
c Enter the amount of reserves on hand	13c			
14a Did the organization receive any payments for indoor tanning services during the tax year?			14a	No
b If "Yes," has it filed a Form 720 to report these payments? If "No," provide an explanation in Schedule O . . .			14b	
15 Is the organization subject to the section 4960 tax on payment(s) of more than \$1,000,000 in remuneration or excess parachute payment(s) during the year? If "Yes," see instructions and file Form 4720, Schedule N			15	No
16 Is the organization an educational institution subject to the section 4968 excise tax on net investment income? . . . If "Yes," complete Form 4720, Schedule O			16	No

Part VI

Governance, Management, and Disclosure For each "Yes" response to lines 2 through 7b below, and for a "No" response to lines 8a, 8b, or 10b below, describe the circumstances, processes, or changes in Schedule O. See instructions.

Check if Schedule O contains a response or note to any line in this Part VI ☒

Section A. Governing Body and Management

		Yes	No
1a	Enter the number of voting members of the governing body at the end of the tax year	15	
If there are material differences in voting rights among members of the governing body, or if the governing body delegated broad authority to an executive committee or similar committee, explain in Schedule O			
b	Enter the number of voting members included in line 1a, above, who are independent	14	
2	Did any officer, director, trustee, or key employee have a family relationship or a business relationship with any other officer, director, trustee, or key employee?		No
3	Did the organization delegate control over management duties customarily performed by or under the direct supervision of officers, directors or trustees, or key employees to a management company or other person?		No
4	Did the organization make any significant changes to its governing documents since the prior Form 990 was filed?		No
5	Did the organization become aware during the year of a significant diversion of the organization's assets?		No
6	Did the organization have members or stockholders?		No
7a	Did the organization have members, stockholders, or other persons who had the power to elect or appoint one or more members of the governing body?		No
b	Are any governance decisions of the organization reserved to (or subject to approval by) members, stockholders, or persons other than the governing body?		No
8	Did the organization contemporaneously document the meetings held or written actions undertaken during the year by the following:		
a	The governing body?	Yes	
b	Each committee with authority to act on behalf of the governing body?	Yes	
9	Is there any officer, director, trustee, or key employee listed in Part VII, Section A, who cannot be reached at the organization's mailing address? If "Yes," provide the names and addresses in Schedule O		No

Section B. Policies (This Section B requests information about policies not required by the Internal Revenue Code.)

		Yes	No
10a	Did the organization have local chapters, branches, or affiliates?	Yes	
b	If "Yes," did the organization have written policies and procedures governing the activities of such chapters, affiliates, and branches to ensure their operations are consistent with the organization's exempt purposes?	Yes	
11a	Has the organization provided a complete copy of this Form 990 to all members of its governing body before filing the form?	Yes	
b	Describe in Schedule O the process, if any, used by the organization to review this Form 990		
12a	Did the organization have a written conflict of interest policy? If "No," go to line 13	Yes	
b	Were officers, directors, or trustees, and key employees required to disclose annually interests that could give rise to conflicts?	Yes	
c	Did the organization regularly and consistently monitor and enforce compliance with the policy? If "Yes," describe in Schedule O how this was done	Yes	
13	Did the organization have a written whistleblower policy?	Yes	
14	Did the organization have a written document retention and destruction policy?	Yes	
15	Did the process for determining compensation of the following persons include a review and approval by independent persons, comparability data, and contemporaneous substantiation of the deliberation and decision?		
a	The organization's CEO, Executive Director, or top management official	Yes	
b	Other officers or key employees of the organization	Yes	
If "Yes" to line 15a or 15b, describe the process in Schedule O (see instructions)			
16a	Did the organization invest in, contribute assets to, or participate in a joint venture or similar arrangement with a taxable entity during the year?		No
b	If "Yes," did the organization follow a written policy or procedure requiring the organization to evaluate its participation in joint venture arrangements under applicable federal tax law, and take steps to safeguard the organization's exempt status with respect to such arrangements?		

Section C. Disclosure

17 List the states with which a copy of this Form 990 is required to be filed ▶

CT, NY, AL, CA, FL, GA, IL, KS, KY, MA, MD, MI, MN, MS, NC, NH, NJ, NM, OK, OR, PA, RI, SC, TN, UT, VA, WI, WV, AR, HI

18 Section 6104 requires an organization to make its Form 1023 (or 1024-A if applicable), 990, and 990-T (501(c)(3)s only) available for public inspection. Indicate how you made these available. Check all that apply.

☒ Own website ☐ Another's website ☒ Upon request ☐ Other (explain in Schedule O)

19 Describe in Schedule O whether (and if so, how) the organization made its governing documents, conflict of interest policy, and financial statements available to the public during the tax year.

20 State the name, address, and telephone number of the person who possesses the organization's books and records.

▶ VINCENT MURPHY 1900 CROWN COLONY DRIVE 3RD FLOOR QUINCY, MA 02169 (617) 249-7300

Part VII**Compensation of Officers, Directors, Trustees, Key Employees, Highest Compensated Employees, and Independent Contractors**Check if Schedule O contains a response or note to any line in this Part VII ☐**Section A. Officers, Directors, Trustees, Key Employees, and Highest Compensated Employees****1a** Complete this table for all persons required to be listed. Report compensation for the calendar year ending with or within the organization's tax year.

- List all of the organization's **current** officers, directors, trustees (whether individuals or organizations), regardless of amount of compensation. Enter -0- in columns (D), (E), and (F) if no compensation was paid.
- List all of the organization's **current** key employees, if any. See instructions for definition of "key employee."
- List the organization's five **current** highest compensated employees (other than an officer, director, trustee or key employee) who received reportable compensation (Box 5 of Form W-2 and/or Box 7 of Form 1099-MISC) of more than \$100,000 from the organization and any related organizations.
- List all of the organization's **former** officers, key employees, or highest compensated employees who received more than \$100,000 of reportable compensation from the organization and any related organizations.
- List all of the organization's **former directors or trustees** that received, in the capacity as a former director or trustee of the organization, more than \$10,000 of reportable compensation from the organization and any related organizations.

See instructions for the order in which to list the persons above.

☐ Check this box if neither the organization nor any related organization compensated any current officer, director, or trustee

(A) Name and title	(B) Average hours per week (list any hours for related organizations below dotted line)	(C) Position (do not check more than one box, unless person is both an officer and a director/trustee)						(D) Reportable compensation from the organization (W-2/1099-MISC)	(E) Reportable compensation from related organizations (W-2/1099-MISC)	(F) Estimated amount of other compensation from the organization and related organizations
		Individual trustee or director	Institutional Trustee	Officer	Key employee	Highest compensated employee	Former			
(1) SHELDON M SCHUSTER PHD VICE CHAIRMAN	2 00	X		X				0	0	0
(2) STEVEN GROSSMAN SECRETARY	8 00	X		X				0	0	0
(3) MARSHALL L SUMMAR MD CHAIRMAN	10 00	X		X				0	0	0
(4) FREDERICK BARR MD DIRECTOR	1 00	X						0	0	0
(5) RONALD J BARTEK DIRECTOR	5 00	X						0	0	0
(6) SUSAN HEDSTROM DIRECTOR	2 00	X						0	0	0
(7) VICKI MCCARRELL DIRECTOR	4 00	X						0	0	0
(8) JIM PALMA DIRECTOR	3 00	X						0	0	0
(9) PETER SALTONSTALL PRESIDENT/CEO	35 00	X		X				399,286	0	24,836
(10) SUSAN BERRY DIRECTOR	2 00	X						0	0	0
(11) KAY HOLCOMBE DIRECTOR	2 00	X						0	0	0
(12) NEIL HORIKOSHI DIRECTOR	2 00	X						0	0	0
(13) SHAFALI JESTE DIRECTOR	1 00	X						0	0	0
(14) PHILIP PEARL DIRECTOR	2 00	X						0	0	0
(15) MIKE PORATH DIRECTOR	2 00	X						0	0	0
(16) PAMELA GAVIN CHIEF OPERATING OFFICER	35 00			X				314,643	0	22,121
(17) VINCENT J MURPHY JR VP FINANCE	35 00			X				122,652	0	29,570

Part VII Section A. Officers, Directors, Trustees, Key Employees, and Highest Compensated Employees (continued)

(A) Name and title	(B) Average hours per week (list any hours for related organizations below dotted line)	(C) Position (do not check more than one box, unless person is both an officer and a director/trustee)						(D) Reportable compensation from the organization (W-2/1099-MISC)	(E) Reportable compensation from related organizations (W-2/1099-MISC)	(F) Estimated amount of other compensation from the organization and related organizations
		Individual trustee or director	Institutional Trustee	Officer	Key employee	Highest compensated employee	Former			
(18) TIM EHRHARD DIRECTOR OF IT	35 00					X		157,641	0	31,257
(19) ALEXA MOORE VP OF DEVELOPMENT	35 00					X		204,227	0	32,940
(20) JILL POLLANDER DIRECTOR OF PATIENT SERVICES	35 00					X		123,058	0	21,704
(21) RACHEL SHER VP POLICY & REGULATORY AFFAIRS	35 00					X		193,229	0	8,982
(22) JAMES BERG PRINCIPAL SOFTWARE ARCHITECT	35 00					X		121,494	0	37,063
1b Sub-Total										
c Total from continuation sheets to Part VII, Section A										
d Total (add lines 1b and 1c)								1,636,230	0	208,473

2 Total number of individuals (including but not limited to those listed above) who received more than \$100,000 of reportable compensation from the organization ► 15

	Yes	No
3 Did the organization list any former officer, director or trustee, key employee, or highest compensated employee on line 1a? <i>If "Yes," complete Schedule J for such individual</i>		No
4 For any individual listed on line 1a, is the sum of reportable compensation and other compensation from the organization and related organizations greater than \$150,000? <i>If "Yes," complete Schedule J for such individual</i>	Yes	
5 Did any person listed on line 1a receive or accrue compensation from any unrelated organization or individual for services rendered to the organization? <i>If "Yes," complete Schedule J for such person</i>		No

Section B. Independent Contractors

1 Complete this table for your five highest compensated independent contractors that received more than \$100,000 of compensation from the organization. Report compensation for the calendar year ending with or within the organization's tax year.

(A) Name and business address	(B) Description of services	(C) Compensation
CLOUD FOR GOOD LLC 1854A HENDERSONVILLE RD 252 ASHEVILLE, NC 28803	IT CONSULTANT	136,111

2 Total number of independent contractors (including but not limited to those listed above) who received more than \$100,000 of compensation from the organization ► 1

Form 990 (2019)		Page 9				
Part VIII		Statement of Revenue				
Check if Schedule O contains a response or note to any line in this Part VIII ☐						
		(A) Total revenue	(B) Related or exempt function revenue	(C) Unrelated business revenue	(D) Revenue excluded from tax under sections 512 - 514	
Contributions, Gifts, Grants and Other Similar Amounts	1a Federated campaigns	1a				
	b Membership dues	1b	1,665,303			
	c Fundraising events	1c				
	d Related organizations	1d				
	e Government grants (contributions)	1e				
	f All other contributions, gifts, grants, and similar amounts not included above	1f	41,978,717			
	g Noncash contributions included in lines 1a - 1f \$	1g	118,421			
	h Total. Add lines 1a-1f ▶		43,644,020			
Program Service Revenue	2a PATIENT ASSISTANCE FEE	Business Code				
		624100	5,008,574	5,008,574		
	b PROGRAMMATIC EVENTS AN	624100	2,399,519	2,399,519		
	c RESEARCH FEES	624100	576,127	576,127		
	d REGISTRY, WEB SUBSCRIP	624100	234,128	234,128		
	e DRUG, TRAVEL AND LODGI	624100	174,162	174,162		
	f All other program service revenue					
g Total. Add lines 2a-2f. ▶		8,392,510				
Other Revenue	3 Investment income (including dividends, interest, and other similar amounts) ▶		595,629		595,629	
	4 Income from investment of tax-exempt bond proceeds ▶					
	5 Royalties ▶					
	6a Gross rents	(i) Real	(ii) Personal			
		6a				
		b Less rental expenses	6b			
		c Rental income or (loss)	6c			
	d Net rental income or (loss) ▶					
	7a Gross amount from sales of assets other than inventory	(i) Securities	(ii) Other			
		7a				
		b Less cost or other basis and sales expenses	7b			
		c Gain or (loss)	7c			
	d Net gain or (loss) ▶					
	8a Gross income from fundraising events (not including \$ of contributions reported on line 1c) See Part IV, line 18	8a	5,500			
		b Less direct expenses	8b	224,282		
		c Net income or (loss) from fundraising events ▶		-218,782		-218,782
	9a Gross income from gaming activities See Part IV, line 19	9a				
		b Less direct expenses	9b			
		c Net income or (loss) from gaming activities ▶				
	10a Gross sales of inventory, less returns and allowances	10a				
b Less cost of goods sold		10b				
c Net income or (loss) from sales of inventory ▶						
Miscellaneous Revenue		Business Code				
11a						
b						
c						
d All other revenue						
e Total. Add lines 11a-11d ▶						
12 Total revenue. See instructions ▶		52,413,377	8,392,510	0	376,847	

Form 990 (2019)

Part IX Statement of Functional Expenses

Section 501(c)(3) and 501(c)(4) organizations must complete all columns. All other organizations must complete column (A).

Check if Schedule O contains a response or note to any line in this Part IX ☐

Do not include amounts reported on lines 6b, 7b, 8b, 9b, and 10b of Part VIII.	(A) Total expenses	(B) Program service expenses	(C) Management and general expenses	(D) Fundraising expenses
1 Grants and other assistance to domestic organizations and domestic governments. See Part IV, line 21.	535,130	535,130		
2 Grants and other assistance to domestic individuals. See Part IV, line 22.	30,812,906	30,812,906		
3 Grants and other assistance to foreign organizations, foreign governments, and foreign individuals. See Part IV, lines 15 and 16.				
4 Benefits paid to or for members.				
5 Compensation of current officers, directors, trustees, and key employees.	947,732	370,709	296,611	280,412
6 Compensation not included above, to disqualified persons (as defined under section 4958(f)(1)) and persons described in section 4958(c)(3)(B).				
7 Other salaries and wages.	4,621,791	2,424,728	1,584,541	612,522
8 Pension plan accruals and contributions (include section 401 (k) and 403(b) employer contributions).	227,791	132,588	64,508	30,695
9 Other employee benefits.	450,852	335,388	46,464	69,000
10 Payroll taxes.	382,509	178,533	142,915	61,061
11 Fees for services (non-employees):				
a Management.				
b Legal.	210,828	97,984	102,275	10,569
c Accounting.	54,342		54,342	
d Lobbying.				
e Professional fundraising services. See Part IV, line 17.				
f Investment management fees.				
g Other (If line 11g amount exceeds 10% of line 25, column (A) amount, list line 11g expenses on Schedule O).	390,592	254,629	85,854	50,109
12 Advertising and promotion.				
13 Office expenses.				
14 Information technology.	328,595	81,781	163,025	83,789
15 Royalties.				
16 Occupancy.	538,733	284,649	173,268	80,816
17 Travel.	210,806	205,780	5,026	
18 Payments of travel or entertainment expenses for any federal, state, or local public officials.				
19 Conferences, conventions, and meetings.	1,154,423	917,053	137,251	100,119
20 Interest.				
21 Payments to affiliates.				
22 Depreciation, depletion, and amortization.	545,820	509,778	21,811	14,231
23 Insurance.				
24 Other expenses. Itemize expenses not covered above (List miscellaneous expenses in line 24e. If line 24e amount exceeds 10% of line 25, column (A) amount, list line 24e expenses on Schedule O):				
a MISCELLANEOUS	376,844	235,162	50,206	91,476
b				
c				
d				
e All other expenses.				
25 Total functional expenses. Add lines 1 through 24e.	41,789,694	37,376,798	2,928,097	1,484,799
26 Joint costs. Complete this line only if the organization reported in column (B) joint costs from a combined educational campaign and fundraising solicitation. Check here ☐ if following SOP 98-2 (ASC 958-720)				

Part X Balance SheetCheck if Schedule O contains a response or note to any line in this Part IX ☐

		(A) Beginning of year		(B) End of year
Assets	1 Cash—non-interest-bearing	38,371,222	1	2,468,342
	2 Savings and temporary cash investments	7,705,613	2	45,239,712
	3 Pledges and grants receivable, net		3	
	4 Accounts receivable, net	2,687,602	4	11,775,250
	5 Loans and other payables to any current or former officer, director, trustee, key employee, creator or founder, substantial contributor, or 35% controlled entity or family member of any of these persons		5	
	6 Loans and other receivables from other disqualified persons (as defined under section 4958(f)(1)), and persons described in section 4958(c)(3)(B)		6	
	7 Notes and loans receivable, net		7	
	8 Inventories for sale or use		8	
	9 Prepaid expenses and deferred charges	316,998	9	353,136
	10a Land, buildings, and equipment—cost or other basis—Complete Part VI of Schedule D	10a 4,260,301		
	b Less—accumulated depreciation	10b 2,772,540	1,625,587	10c 1,487,761
	11 Investments—publicly traded securities		11	136,831
	12 Investments—other securities—See Part IV, line 11		12	
	13 Investments—program-related—See Part IV, line 11		13	
	14 Intangible assets	107,063	14	189,191
	15 Other assets—See Part IV, line 11	23,943	15	100,873
16 Total assets. Add lines 1 through 15 (must equal line 34)	50,838,028	16	61,751,096	
Liabilities	17 Accounts payable and accrued expenses	595,138	17	921,186
	18 Grants payable	474,078	18	746,474
	19 Deferred revenue	585,652	19	223,059
	20 Tax-exempt bond liabilities		20	
	21 Escrow or custodial account liability—Complete Part IV of Schedule D		21	
	22 Loans and other payables to any current or former officer, director, trustee, key employee, creator or founder, substantial contributor, or 35% controlled entity or family member of any of these persons		22	
	23 Secured mortgages and notes payable to unrelated third parties	368,468	23	304,223
	24 Unsecured notes and loans payable to unrelated third parties		24	
	25 Other liabilities (including federal income tax, payables to related third parties, and other liabilities not included on lines 17 - 24)—Complete Part X of Schedule D	104,052	25	136,831
	26 Total liabilities. Add lines 17 through 25	2,127,388	26	2,331,773
Net Assets or Fund Balances	Organizations that follow FASB ASC 958, check here ☒ and complete lines 27, 28, 32, and 33.			
	27 Net assets without donor restrictions	3,289,240	27	5,041,320
	28 Net assets with donor restrictions	45,421,400	28	54,378,003
	Organizations that do not follow FASB ASC 958, check here ☐ and complete lines 29 through 33.			
	29 Capital stock or trust principal, or current funds		29	
	30 Paid-in or capital surplus, or land, building or equipment fund		30	
	31 Retained earnings, endowment, accumulated income, or other funds		31	
	32 Total net assets or fund balances	48,710,640	32	59,419,323
33 Total liabilities and net assets/fund balances	50,838,028	33	61,751,096	

Part XI Reconciliation of Net AssetsCheck if Schedule O contains a response or note to any line in this Part XI ☐

1	Total revenue (must equal Part VIII, column (A), line 12)	1	52,413,377
2	Total expenses (must equal Part IX, column (A), line 25)	2	41,789,694
3	Revenue less expenses Subtract line 2 from line 1	3	10,623,683
4	Net assets or fund balances at beginning of year (must equal Part X, line 33, column (A))	4	48,710,640
5	Net unrealized gains (losses) on investments	5	
6	Donated services and use of facilities	6	
7	Investment expenses	7	
8	Prior period adjustments	8	85,000
9	Other changes in net assets or fund balances (explain in Schedule O)	9	0
10	Net assets or fund balances at end of year Combine lines 3 through 9 (must equal Part X, line 33, column (B))	10	59,419,323

Part XII Financial Statements and ReportingCheck if Schedule O contains a response or note to any line in this Part XII ☒

	Yes	No
1 Accounting method used to prepare the Form 990 ☐ Cash ☒ Accrual ☐ Other _____ If the organization changed its method of accounting from a prior year or checked "Other," explain in Schedule O		
2a Were the organization's financial statements compiled or reviewed by an independent accountant? If 'Yes,' check a box below to indicate whether the financial statements for the year were compiled or reviewed on a separate basis, consolidated basis, or both ☐ Separate basis ☐ Consolidated basis ☐ Both consolidated and separate basis		No
b Were the organization's financial statements audited by an independent accountant? If 'Yes,' check a box below to indicate whether the financial statements for the year were audited on a separate basis, consolidated basis, or both ☒ Separate basis ☐ Consolidated basis ☐ Both consolidated and separate basis	Yes	
c If "Yes," to line 2a or 2b, does the organization have a committee that assumes responsibility for oversight of the audit, review, or compilation of its financial statements and selection of an independent accountant? If the organization changed either its oversight process or selection process during the tax year, explain in Schedule O	Yes	
3a As a result of a federal award, was the organization required to undergo an audit or audits as set forth in the Single Audit Act and OMB Circular A-133?		No
b If "Yes," did the organization undergo the required audit or audits? If the organization did not undergo the required audit or audits, explain why in Schedule O and describe any steps taken to undergo such audits		

Additional Data

Software ID:
Software Version:
EIN: 13-3223946
Name: NATIONAL ORGANIZATION FOR RARE
DISORDERS INC

Form 990 (2019)

Form 990, Part III, Line 4a:

PATIENT ASSISTANCE PROGRAMS PROVIDE FINANCIAL ASSISTANCE TO HELP ELIGIBLE PATIENTS ACCESS LIFESAVING THERAPIES AND SERVICES PRESCRIBED BY THEIR PHYSICIANS IN 2019 NORD PROVIDED FINANCIAL ASSISTANCE TO 8,612 PEOPLE WITH RARE DISEASES IN ADDITION, NORD WORKS WITH ORGANIZATIONS CONDUCTING CLINICAL TRIALS OF NEW TREATMENTS IN ARRANGING FOR PATIENTS WITH RARE DISEASES AND FAMILY MEMBERS TO TRAVEL TO THE SITES WHERE THE TRIALS ARE BEING CONDUCTED IN 2019, THERE WERE 381 PATIENTS THAT NORD ASSISTED AS PART OF THAT SPECIAL CLINICAL TRIAL TRAVEL ASSISTANCE PROGRAM

Form 990, Part III, Line 4b:

NORD EDUCATIONAL INITIATIVES STRIVE TO EMPOWER PATIENTS AND THEIR FAMILIES, INFORM STUDENTS OF ALL AGES, AND SUPPORT THE VITALLY IMPORTANT WORK OF PHYSICIANS AND OTHER HEALTHCARE PROFESSIONALS IN CREATING A BETTER UNDERSTANDING OF RARE DISEASES. THIS IS DONE THROUGH THE DEVELOPMENT OF NORD'S RARE DISEASE DATABASE, EDUCATIONAL WEBINARS AND VIDEOS, AND ROBUST EDUCATIONAL PROGRAMMING THROUGH NORD'S CME PARTNERSHIPS AND AT NORD'S RARE DISEASES AND ORPHAN PRODUCTS BREAKTHROUGH SUMMIT (RARE SUMMIT). IN 2019 OVER 800 PEOPLE ATTENDED NORD'S RARE SUMMIT WHERE KEY STAKEHOLDER IN THE RARE DISEASE SPACE GATHER TO LEARN, CONNECT, AND CREATE POSITIVE CHANGE FOR THE BROADER RARE DISEASE COMMUNITY. ALSO, IN 2019 THERE WERE OVER 12.5 MILLION VISITORS TO THE ORGANIZATION'S WEBSITE TO READ NORD'S RARE DISEASE REPORTS WHICH OFFER INFORMATION ABOUT EACH RARE DISEASE IN EASY TO UNDERSTAND LANGUAGE.

Form 990, Part III, Line 4c:

IN 2019, NORD HAS CONTINUED TO DEVELOP ITS NATUARL HISTORY/REGISTRYPLATFORM TO HELP RESEARCHERS BETTER UNDERSTAND THE PATIENT EXPERIENCEAND PROMOTE DEVELOPMENT OF INNOVATIVE, SAFE AND EFFECTIVE THERAPIES ASOF DECEMBER 31, 2019, THERE WERE 10,238 PARTICIPANTS ACROSS 30DIEASE-SPECIFIC DATABASES AS PART OF NORD'S REGISTRY PROGRAM IN ADDITION, NORD AWARDED 10 GRANTS IN 2019 TO SUPPORT RESEARCH OF RARE DISEASES THESE GRANTS ARE FUNDED BY CONTRIBUTIONS FROM THE PUBLIC, PATIENTS AND THEIR FAMILIES, AND PATEINT ORGANIZATIONS

Form 990, Part III - 4 Program Service Accomplishments (See the Instructions)

Describe the exempt purpose achievements for each of the organization's three largest program services by expenses. Section 501(c)(3) and (4) organizations and 4947(a)(1) trusts are required to report the amount of grants and allocations to others, the total expenses, and revenue, if any, for each program service reported.

(Code) (Expenses \$ 1,142,479 including grants of \$) (Revenue \$ 2,413,919)

NORD'S ADVOCACY EFFORTS ARE FOCUSED ON SERVING AS A LIASON BETWEEN THERARE DISEASE COMMUNITY AND THE VARIOUS ORGANIZATIONS AND INSTITUTIONSTHAT HAVE A DIRECT IMPACT ON THE LIVES OF THE 30 MILLION AMERICANSLIVING WITH RARE DISEASES NORD ENGAGES ALL TYPES OF ORGANIZATIONS,INCLUDING STATE AND FEDERAL AGENCIES AND LEGISLATORS, OTHER NON-PROFITORGANIZATIONS, AND FOR-PROFIT ORGANIZATIONS TO HELP RAISE AWARENESSAROUND THE NEEDS OF RARE DISEASE PATIENTS AND TO COLLECTIVELYCONTRIBUTE TO REALIZING SOLUTIONS POSITIVELY IMPACT OUR DIVERSECOMMUNITY

(Code) (Expenses \$ 789,154 including grants of \$) (Revenue \$ 3,000)

MEMBERSHIP NORD WAS FOUNDED ON THE PRINCIPLES OF COLLABORATION AND A UNITED VOICE, AND WE PROVIDE GUIDANCE AND SUPPORT AT ALL PHASES OF DEVELOPMENT, AS ORGANIZATIONS EVOLVE NORD OFFERS ITS MEMBERS EDUCATIONAL WEBINARS AND REGIONAL MEMBERSHIP MEETINGS PROVIDE OPPORTUNITIES TO INTERACT WITH OTHER LEADERSHIP OF OTHER PATIENT ORGANIZATIONS AND TO BUILD CAPACITY BY ADOPTING BEST PRACTICES AS OF DECEMBER 31, 2019 THERE WERE 296 PATIENT ORGANIZATIONS THAT WERE MEMBERS

SCHEDULE A
(Form 990 or 990-EZ)

Department of the Treasury
Internal Revenue Service

Public Charity Status and Public Support
Complete if the organization is a section 501(c)(3) organization or a section 4947(a)(1) nonexempt charitable trust.
▶ Attach to Form 990 or Form 990-EZ.
▶ Go to www.irs.gov/Form990 for instructions and the latest information.

OMB No 1545-0047

2019

Open to Public Inspection

Name of the organization
NATIONAL ORGANIZATION FOR RARE DISORDERS INC

Employer identification number
13-3223946

Part I Reason for Public Charity Status (All organizations must complete this part.) See instructions.

The organization is not a private foundation because it is (For lines 1 through 12, check only one box)

- 1 ☐ A church, convention of churches, or association of churches described in **section 170(b)(1)(A)(i).**
- 2 ☐ A school described in **section 170(b)(1)(A)(ii).** (Attach Schedule E (Form 990 or 990-EZ))
- 3 ☐ A hospital or a cooperative hospital service organization described in **section 170(b)(1)(A)(iii).**
- 4 ☐ A medical research organization operated in conjunction with a hospital described in **section 170(b)(1)(A)(iii).** Enter the hospital's name, city, and state
- 5 ☐ An organization operated for the benefit of a college or university owned or operated by a governmental unit described in **section 170(b)(1)(A)(iv).** (Complete Part II)
- 6 ☐ A federal, state, or local government or governmental unit described in **section 170(b)(1)(A)(v).**
- 7 ☒ An organization that normally receives a substantial part of its support from a governmental unit or from the general public described in **section 170(b)(1)(A)(vi).** (Complete Part II)
- 8 ☐ A community trust described in **section 170(b)(1)(A)(vi)** (Complete Part II)
- 9 ☐ An agricultural research organization described in **170(b)(1)(A)(ix)** operated in conjunction with a land-grant college or university or a non-land grant college of agriculture See instructions Enter the name, city, and state of the college or university
- 10 ☐ An organization that normally receives (1) more than 33 1/3% of its support from contributions, membership fees, and gross receipts from activities related to its exempt functions—subject to certain exceptions, and (2) no more than 33 1/3% of its support from gross investment income and unrelated business taxable income (less section 511 tax) from businesses acquired by the organization after June 30, 1975 See **section 509(a)(2).** (Complete Part III)
- 11 ☐ An organization organized and operated exclusively to test for public safety See **section 509(a)(4).**
- 12 ☐ An organization organized and operated exclusively for the benefit of, to perform the functions of, or to carry out the purposes of one or more publicly supported organizations described in **section 509(a)(1)** or **section 509(a)(2).** See **section 509(a)(3).** Check the box in lines 12a through 12d that describes the type of supporting organization and complete lines 12e, 12f, and 12g
- a ☐ **Type I.** A supporting organization operated, supervised, or controlled by its supported organization(s), typically by giving the supported organization(s) the power to regularly appoint or elect a majority of the directors or trustees of the supporting organization **You must complete Part IV, Sections A and B.**
- b ☐ **Type II.** A supporting organization supervised or controlled in connection with its supported organization(s), by having control or management of the supporting organization vested in the same persons that control or manage the supported organization(s) **You must complete Part IV, Sections A and C.**
- c ☐ **Type III functionally integrated.** A supporting organization operated in connection with, and functionally integrated with, its supported organization(s) (see instructions) **You must complete Part IV, Sections A, D, and E.**
- d ☐ **Type III non-functionally integrated.** A supporting organization operated in connection with its supported organization(s) that is not functionally integrated The organization generally must satisfy a distribution requirement and an attentiveness requirement (see instructions) **You must complete Part IV, Sections A and D, and Part V.**
- e ☐ Check this box if the organization received a written determination from the IRS that it is a Type I, Type II, Type III functionally integrated, or Type III non-functionally integrated supporting organization
- f Enter the number of supported organizations _____
- g Provide the following information about the supported organization(s)

(i) Name of supported organization	(ii) EIN	(iii) Type of organization (described on lines 1- 10 above (see instructions))	(iv) Is the organization listed in your governing document?		(v) Amount of monetary support (see instructions)	(vi) Amount of other support (see instructions)
			Yes	No		
Total						

Part II

Support Schedule for Organizations Described in Sections 170(b)(1)(A)(iv) and 170(b)(1)(A)(vi)

(Complete only if you checked the box on line 5, 7, or 8 of Part I or if the organization failed to qualify under Part III.
If the organization failed to qualify under the tests listed below, please complete Part III.)

Section A. Public Support

Calendar year (or fiscal year beginning in) ▶	(a) 2015	(b) 2016	(c) 2017	(d) 2018	(e) 2019	(f) Total
1 Gifts, grants, contributions, and membership fees received (Do not include any "unusual grant.")	20,322,996	37,862,150	48,281,104	42,070,943	45,370,270	193,907,463
2 Tax revenues levied for the organization's benefit and either paid to or expended on its behalf						
3 The value of services or facilities furnished by a governmental unit to the organization without charge						
4 Total. Add lines 1 through 3	20,322,996	37,862,150	48,281,104	42,070,943	45,370,270	193,907,463
5 The portion of total contributions by each person (other than a governmental unit or publicly supported organization) included on line 1 that exceeds 2% of the amount shown on line 11, column (f)						115,887,981
6 Public support. Subtract line 5 from line 4						78,019,482

Section B. Total Support

Calendar year (or fiscal year beginning in) ▶	(a) 2015	(b) 2016	(c) 2017	(d) 2018	(e) 2019	(f) Total
7 Amounts from line 4	20,322,996	37,862,150	48,281,104	42,070,943	45,370,270	193,907,463
8 Gross income from interest, dividends, payments received on securities loans, rents, royalties and income from similar sources	157,483	418,492	21,741	145,033	595,629	1,338,378
9 Net income from unrelated business activities, whether or not the business is regularly carried on						
10 Other income. Do not include gain or loss from the sale of capital assets (Explain in Part VI.)						
11 Total support. Add lines 7 through 10						195,245,841
12 Gross receipts from related activities, etc. (see instructions)					12	21,498,279

13

First five years. If the Form 990 is for the organization's first, second, third, fourth, or fifth tax year as a section 501(c)(3) organization, check this box and **stop here** ▶ ☐

Section C. Computation of Public Support Percentage

14 Public support percentage for 2019 (line 6, column (f) divided by line 11, column (f))	14	39.960 %
15 Public support percentage for 2018 Schedule A, Part II, line 14	15	44.310 %

16a

33 1/3% support test—2019.

If the organization did not check the box on line 13, and line 14 is 33 1/3% or more, check this box and **stop here.** The organization qualifies as a publicly supported organization ▶ ☒

b

33 1/3% support test—2018.

If the organization did not check a box on line 13 or 16a, and line 15 is 33 1/3% or more, check this box and **stop here.** The organization qualifies as a publicly supported organization ▶ ☐

17a

10%-facts-and-circumstances test—2019.

If the organization did not check a box on line 13, 16a, or 16b, and line 14 is 10% or more, and if the organization meets the "facts-and-circumstances" test, check this box and **stop here.** Explain in Part VI how the organization meets the "facts-and-circumstances" test. The organization qualifies as a publicly supported organization ▶ ☐

b

10%-facts-and-circumstances test—2018.

If the organization did not check a box on line 13, 16a, 16b, or 17a, and line 15 is 10% or more, and if the organization meets the "facts-and-circumstances" test, check this box and **stop here.** Explain in Part VI how the organization meets the "facts-and-circumstances" test. The organization qualifies as a publicly supported organization ▶ ☐

18

Private foundation.

If the organization did not check a box on line 13, 16a, 16b, 17a, or 17b, check this box and see instructions ▶ ☐

Schedule A (Form 990 or 990-EZ) 2019

Part III Support Schedule for Organizations Described in Section 509(a)(2)

(Complete only if you checked the box on line 10 of Part I or if the organization failed to qualify under Part II. If the organization fails to qualify under the tests listed below, please complete Part II.)

Section A. Public Support

Calendar year (or fiscal year beginning in) ►	(a) 2015	(b) 2016	(c) 2017	(d) 2018	(e) 2019	(f) Total
1 Gifts, grants, contributions, and membership fees received (Do not include any "unusual grants.")						
2 Gross receipts from admissions, merchandise sold or services performed, or facilities furnished in any activity that is related to the organization's tax-exempt purpose						
3 Gross receipts from activities that are not an unrelated trade or business under section 513						
4 Tax revenues levied for the organization's benefit and either paid to or expended on its behalf						
5 The value of services or facilities furnished by a governmental unit to the organization without charge						
6 Total. Add lines 1 through 5						
7a Amounts included on lines 1, 2, and 3 received from disqualified persons						
b Amounts included on lines 2 and 3 received from other than disqualified persons that exceed the greater of \$5,000 or 1% of the amount on line 13 for the year						
c Add lines 7a and 7b						
8 Public support. (Subtract line 7c from line 6.)						

Section B. Total Support

Calendar year (or fiscal year beginning in) ►	(a) 2015	(b) 2016	(c) 2017	(d) 2018	(e) 2019	(f) Total
9 Amounts from line 6						
10a Gross income from interest, dividends, payments received on securities loans, rents, royalties and income from similar sources						
b Unrelated business taxable income (less section 511 taxes) from businesses acquired after June 30, 1975						
c Add lines 10a and 10b						
11 Net income from unrelated business activities not included in line 10b, whether or not the business is regularly carried on						
12 Other income. Do not include gain or loss from the sale of capital assets (Explain in Part VI.)						
13 Total support. (Add lines 9, 10c, 11, and 12.)						

14 First five years. If the Form 990 is for the organization's first, second, third, fourth, or fifth tax year as a section 501(c)(3) organization, check this box and **stop here** ► ☐

Section C. Computation of Public Support Percentage

15 Public support percentage for 2019 (line 8, column (f) divided by line 13, column (f))	15	
16 Public support percentage from 2018 Schedule A, Part III, line 15	16	

Section D. Computation of Investment Income Percentage

17 Investment income percentage for 2019 (line 10c, column (f) divided by line 13, column (f))	17	
18 Investment income percentage from 2018 Schedule A, Part III, line 17	18	

19a 33 1/3% support tests—2019. If the organization did not check the box on line 14, and line 15 is more than 33 1/3%, and line 17 is not more than 33 1/3%, check this box and **stop here**. The organization qualifies as a publicly supported organization ► ☐

b 33 1/3% support tests—2018. If the organization did not check a box on line 14 or line 19a, and line 16 is more than 33 1/3% and line 18 is not more than 33 1/3%, check this box and **stop here**. The organization qualifies as a publicly supported organization ► ☐

20 Private foundation. If the organization did not check a box on line 14, 19a, or 19b, check this box and see instructions ► ☐

Part IV Supporting Organizations

(Complete only if you checked a box on line 12 of Part I. If you checked 12a of Part I, complete Sections A and B. If you checked 12b of Part I, complete Sections A and C. If you checked 12c of Part I, complete Sections A, D, and E. If you checked 12d of Part I, complete Sections A and D, and complete Part V.)

Section A. All Supporting Organizations

	Yes	No
1 Are all of the organization's supported organizations listed by name in the organization's governing documents? <i>If "No," describe in Part VI how the supported organizations are designated. If designated by class or purpose, describe the designation. If historic and continuing relationship, explain.</i>	1	
2 Did the organization have any supported organization that does not have an IRS determination of status under section 509(a)(1) or (2)? <i>If "Yes," explain in Part VI how the organization determined that the supported organization was described in section 509(a)(1) or (2).</i>	2	
3a Did the organization have a supported organization described in section 501(c)(4), (5), or (6)? <i>If "Yes," answer (b) and (c) below.</i>	3a	
b Did the organization confirm that each supported organization qualified under section 501(c)(4), (5), or (6) and satisfied the public support tests under section 509(a)(2)? <i>If "Yes," describe in Part VI when and how the organization made the determination.</i>	3b	
c Did the organization ensure that all support to such organizations was used exclusively for section 170(c)(2)(B) purposes? <i>If "Yes," explain in Part VI what controls the organization put in place to ensure such use.</i>	3c	
4a Was any supported organization not organized in the United States ("foreign supported organization")? <i>If "Yes" and if you checked 12a or 12b in Part I, answer (b) and (c) below.</i>	4a	
b Did the organization have ultimate control and discretion in deciding whether to make grants to the foreign supported organization? <i>If "Yes," describe in Part VI how the organization had such control and discretion despite being controlled or supervised by or in connection with its supported organizations.</i>	4b	
c Did the organization support any foreign supported organization that does not have an IRS determination under sections 501(c)(3) and 509(a)(1) or (2)? <i>If "Yes," explain in Part VI what controls the organization used to ensure that all support to the foreign supported organization was used exclusively for section 170(c)(2)(B) purposes.</i>	4c	
5a Did the organization add, substitute, or remove any supported organizations during the tax year? <i>If "Yes," answer (b) and (c) below (if applicable). Also, provide detail in Part VI, including (i) the names and EIN numbers of the supported organizations added, substituted, or removed, (ii) the reasons for each such action, (iii) the authority under the organization's organizing document authorizing such action, and (iv) how the action was accomplished (such as by amendment to the organizing document).</i>	5a	
b Type I or Type II only. Was any added or substituted supported organization part of a class already designated in the organization's organizing document?	5b	
c Substitutions only. Was the substitution the result of an event beyond the organization's control?	5c	
6 Did the organization provide support (whether in the form of grants or the provision of services or facilities) to anyone other than (i) its supported organizations, (ii) individuals that are part of the charitable class benefited by one or more of its supported organizations, or (iii) other supporting organizations that also support or benefit one or more of the filing organization's supported organizations? <i>If "Yes," provide detail in Part VI.</i>	6	
7 Did the organization provide a grant, loan, compensation, or other similar payment to a substantial contributor (defined in section 4958(c)(3)(C)), a family member of a substantial contributor, or a 35% controlled entity with regard to a substantial contributor? <i>If "Yes," complete Part I of Schedule L (Form 990 or 990-EZ).</i>	7	
8 Did the organization make a loan to a disqualified person (as defined in section 4958) not described in line 7? <i>If "Yes," complete Part I of Schedule L (Form 990 or 990-EZ).</i>	8	
9a Was the organization controlled directly or indirectly at any time during the tax year by one or more disqualified persons as defined in section 4946 (other than foundation managers and organizations described in section 509(a)(1) or (2))? <i>If "Yes," provide detail in Part VI.</i>	9a	
b Did one or more disqualified persons (as defined in line 9a) hold a controlling interest in any entity in which the supporting organization had an interest? <i>If "Yes," provide detail in Part VI.</i>	9b	
c Did a disqualified person (as defined in line 9a) have an ownership interest in, or derive any personal benefit from, assets in which the supporting organization also had an interest? <i>If "Yes," provide detail in Part VI.</i>	9c	
10a Was the organization subject to the excess business holdings rules of section 4943 because of section 4943(f) (regarding certain Type II supporting organizations, and all Type III non-functionally integrated supporting organizations)? <i>If "Yes," answer line 10b below.</i>	10a	
b Did the organization have any excess business holdings in the tax year? <i>(Use Schedule C, Form 4720, to determine whether the organization had excess business holdings.)</i>	10b	

Part IV

Supporting Organizations (continued)

	Yes	No
11 Has the organization accepted a gift or contribution from any of the following persons?		
a A person who directly or indirectly controls, either alone or together with persons described in (b) and (c) below, the governing body of a supported organization?		
b A family member of a person described in (a) above?		
c A 35% controlled entity of a person described in (a) or (b) above? <i>If "Yes" to a, b, or c, provide detail in Part VI</i>		

Section B. Type I Supporting Organizations

	Yes	No
1 Did the directors, trustees, or membership of one or more supported organizations have the power to regularly appoint or elect at least a majority of the organization's directors or trustees at all times during the tax year? <i>If "No," describe in Part VI how the supported organization(s) effectively operated, supervised, or controlled the organization's activities. If the organization had more than one supported organization, describe how the powers to appoint and/or remove directors or trustees were allocated among the supported organizations and what conditions or restrictions, if any, applied to such powers during the tax year.</i>		
2 Did the organization operate for the benefit of any supported organization other than the supported organization(s) that operated, supervised, or controlled the supporting organization? <i>If "Yes," explain in Part VI how providing such benefit carried out the purposes of the supported organization(s) that operated, supervised or controlled the supporting organization.</i>		

Section C. Type II Supporting Organizations

	Yes	No
1 Were a majority of the organization's directors or trustees during the tax year also a majority of the directors or trustees of each of the organization's supported organization(s)? <i>If "No," describe in Part VI how control or management of the supporting organization was vested in the same persons that controlled or managed the supported organization(s).</i>		

Section D. All Type III Supporting Organizations

	Yes	No
1 Did the organization provide to each of its supported organizations, by the last day of the fifth month of the organization's tax year, (i) a written notice describing the type and amount of support provided during the prior tax year, (ii) a copy of the Form 990 that was most recently filed as of the date of notification, and (iii) copies of the organization's governing documents in effect on the date of notification, to the extent not previously provided?		
2 Were any of the organization's officers, directors, or trustees either (i) appointed or elected by the supported organization (s) or (ii) serving on the governing body of a supported organization? <i>If "No," explain in Part VI how the organization maintained a close and continuous working relationship with the supported organization(s).</i>		
3 By reason of the relationship described in (2), did the organization's supported organizations have a significant voice in the organization's investment policies and in directing the use of the organization's income or assets at all times during the tax year? <i>If "Yes," describe in Part VI the role the organization's supported organizations played in this regard.</i>		

Section E. Type III Functionally-Integrated Supporting Organizations

1 Check the box next to the method that the organization used to satisfy the Integral Part Test during the year (see instructions)		
a ☐ The organization satisfied the Activities Test. Complete line 2 below.		
b ☐ The organization is the parent of each of its supported organizations. Complete line 3 below.		
c ☐ The organization supported a governmental entity. Describe in Part VI how you supported a government entity (see instructions).		
2 Activities Test. Answer (a) and (b) below.		
a Did substantially all of the organization's activities during the tax year directly further the exempt purposes of the supported organization(s) to which the organization was responsive? <i>If "Yes," then in Part VI identify those supported organizations and explain how these activities directly furthered their exempt purposes, how the organization was responsive to those supported organizations, and how the organization determined that these activities constituted substantially all of its activities.</i>		
b Did the activities described in (a) constitute activities that, but for the organization's involvement, one or more of the organization's supported organization(s) would have been engaged in? <i>If "Yes," explain in Part VI the reasons for the organization's position that its supported organization(s) would have engaged in these activities but for the organization's involvement.</i>		
3 Parent of Supported Organizations. Answer (a) and (b) below.		
a Did the organization have the power to regularly appoint or elect a majority of the officers, directors, or trustees of each of the supported organizations? <i>Provide details in Part VI.</i>		
b Did the organization exercise a substantial degree of direction over the policies, programs and activities of each of its supported organizations? <i>If "Yes," describe in Part VI the role played by the organization in this regard.</i>		

Part V Type III Non-Functionally Integrated 509(a)(3) Supporting Organizations

1 ☐ Check here if the organization satisfied the Integral Part Test as a qualifying trust on Nov. 20, 1970 (explain in Part VI) **See instructions.** All other Type III non-functionally integrated supporting organizations must complete Sections A through E

Section A - Adjusted Net Income		(A) Prior Year	(B) Current Year (optional)
1 Net short-term capital gain	1		
2 Recoveries of prior-year distributions	2		
3 Other gross income (see instructions)	3		
4 Add lines 1 through 3	4		
5 Depreciation and depletion	5		
6 Portion of operating expenses paid or incurred for production or collection of gross income or for management, conservation, or maintenance of property held for production of income (see instructions)	6		
7 Other expenses (see instructions)	7		
8 Adjusted Net Income (subtract lines 5, 6 and 7 from line 4)	8		
Section B - Minimum Asset Amount		(A) Prior Year	(B) Current Year (optional)
1 Aggregate fair market value of all non-exempt-use assets (see instructions for short tax year or assets held for part of year)	1		
a Average monthly value of securities	1a		
b Average monthly cash balances	1b		
c Fair market value of other non-exempt-use assets	1c		
d Total (add lines 1a, 1b, and 1c)	1d		
e Discount claimed for blockage or other factors (explain in detail in Part VI)			
2 Acquisition indebtedness applicable to non-exempt use assets	2		
3 Subtract line 2 from line 1d	3		
4 Cash deemed held for exempt use Enter 1-1/2% of line 3 (for greater amount, see instructions)	4		
5 Net value of non-exempt-use assets (subtract line 4 from line 3)	5		
6 Multiply line 5 by .035	6		
7 Recoveries of prior-year distributions	7		
8 Minimum Asset Amount (add line 7 to line 6)	8		
Section C - Distributable Amount			Current Year
1 Adjusted net income for prior year (from Section A, line 8, Column A)	1		
2 Enter 85% of line 1	2		
3 Minimum asset amount for prior year (from Section B, line 8, Column A)	3		
4 Enter greater of line 2 or line 3	4		
5 Income tax imposed in prior year	5		
6 Distributable Amount. Subtract line 5 from line 4, unless subject to emergency temporary reduction (see instructions)	6		
7 ☐ Check here if the current year is the organization's first as a non-functionally-integrated Type III supporting organization (see instructions)			

Part V Type III Non-Functionally Integrated 509(a)(3) Supporting Organizations (continued)

Section D - Distributions	Current Year
1 Amounts paid to supported organizations to accomplish exempt purposes	
2 Amounts paid to perform activity that directly furthers exempt purposes of supported organizations, in excess of income from activity	
3 Administrative expenses paid to accomplish exempt purposes of supported organizations	
4 Amounts paid to acquire exempt-use assets	
5 Qualified set-aside amounts (prior IRS approval required)	
6 Other distributions (describe in Part VI) See instructions	
7 Total annual distributions. Add lines 1 through 6	
8 Distributions to attentive supported organizations to which the organization is responsive (provide details in Part VI) See instructions	
9 Distributable amount for 2019 from Section C, line 6	
10 Line 8 amount divided by Line 9 amount	

Section E - Distribution Allocations (see instructions)	(i) Excess Distributions	(ii) Underdistributions Pre-2019	(iii) Distributable Amount for 2019
1 Distributable amount for 2019 from Section C, line 6			
2 Underdistributions, if any, for years prior to 2019 (reasonable cause required-- explain in Part VI) See instructions			
3 Excess distributions carryover, if any, to 2019			
a From 2014.			
b From 2015.			
c From 2016.			
d From 2017.			
e From 2018.			
f Total of lines 3a through e			
g Applied to underdistributions of prior years			
h Applied to 2019 distributable amount			
i Carryover from 2014 not applied (see instructions)			
j Remainder Subtract lines 3g, 3h, and 3i from 3f			
4 Distributions for 2019 from Section D, line 7 \$			
a Applied to underdistributions of prior years			
b Applied to 2019 distributable amount			
c Remainder Subtract lines 4a and 4b from 4			
5 Remaining underdistributions for years prior to 2019, if any Subtract lines 3g and 4a from line 2 If the amount is greater than zero, explain in Part VI See instructions			
6 Remaining underdistributions for 2019 Subtract lines 3h and 4b from line 1 If the amount is greater than zero, explain in Part VI See instructions			
7 Excess distributions carryover to 2020. Add lines 3j and 4c			
8 Breakdown of line 7			
a Excess from 2015.			
b Excess from 2016.			
c Excess from 2017.			
d Excess from 2018.			
e Excess from 2019.			

Additional Data

Software ID:
Software Version:
EIN: 13-3223946
Name: NATIONAL ORGANIZATION FOR RARE
DISORDERS INC

Part VI

Supplemental Information. Provide the explanations required by Part II, line 10, Part II, line 17a or 17b, Part III, line 12, Part IV, Section A, lines 1, 2, 3b, 3c, 4b, 4c, 5a, 6, 9a, 9b, 9c, 11a, 11b, and 11c, Part IV, Section B, lines 1 and 2, Part IV, Section C, line 1, Part IV, Section D, lines 2 and 3, Part IV, Section E, lines 1c, 2a, 2b, 3a and 3b, Part V, line 1, Part V, Section B, line 1e, Part V Section D, lines 5, 6, and 8, and Part V, Section E, lines 2, 5, and 6 Also complete this part for any additional information (See instructions)

Facts And Circumstances Test

SCHEDULE C
(Form 990 or 990-EZ)

Department of the Treasury
Internal Revenue Service

Political Campaign and Lobbying Activities

For Organizations Exempt From Income Tax Under section 501(c) and section 527

▶Complete if the organization is described below. ▶Attach to Form 990 or Form 990-EZ.
▶Go to www.irs.gov/Form990 for instructions and the latest information.

OMB No 1545-0047

2019

Open to Public Inspection

If the organization answered "Yes" on Form 990, Part IV, Line 3, or Form 990-EZ, Part V, line 46 (Political Campaign Activities), then

- Section 501(c)(3) organizations Complete Parts I-A and B Do not complete Part I-C
- Section 501(c) (other than section 501(c)(3)) organizations Complete Parts I-A and C below Do not complete Part I-B
- Section 527 organizations Complete Part I-A only

If the organization answered "Yes" on Form 990, Part IV, Line 4, or Form 990-EZ, Part VI, line 47 (Lobbying Activities), then

- Section 501(c)(3) organizations that have filed Form 5768 (election under section 501(h)) Complete Part II-A Do not complete Part II-B
- Section 501(c)(3) organizations that have NOT filed Form 5768 (election under section 501(h)) Complete Part II-B Do not complete Part II-A

If the organization answered "Yes" on Form 990, Part IV, Line 5 (Proxy Tax) (see separate instructions) or Form 990-EZ, Part V, line 35c (Proxy Tax) (see separate instructions), then

- Section 501(c)(4), (5), or (6) organizations Complete Part III

Name of the organization NATIONAL ORGANIZATION FOR RARE DISORDERS INC	Employer identification number 13-3223946
---	---

Part I-A Complete if the organization is exempt under section 501(c) or is a section 527 organization.

- 1 Provide a description of the organization's direct and indirect political campaign activities in Part IV (see instructions for definition of "political campaign activities")
- 2 Political campaign activity expenditures (see instructions) ▶ \$
- 3 Volunteer hours for political campaign activities (see instructions) ▶

Part I-B Complete if the organization is exempt under section 501(c)(3).

- 1 Enter the amount of any excise tax incurred by the organization under section 4955 ▶ \$
- 2 Enter the amount of any excise tax incurred by organization managers under section 4955 ▶ \$
- 3 If the organization incurred a section 4955 tax, did it file Form 4720 for this year? ☐ Yes ☐ No
- 4a Was a correction made? ☐ Yes ☐ No
- b If "Yes," describe in Part IV

Part I-C Complete if the organization is exempt under section 501(c), except section 501(c)(3).

- 1 Enter the amount directly expended by the filing organization for section 527 exempt function activities ▶ \$
- 2 Enter the amount of the filing organization's funds contributed to other organizations for section 527 exempt function activities ▶ \$
- 3 Total exempt function expenditures Add lines 1 and 2 Enter here and on Form 1120-POL, line 17b ▶ \$
- 4 Did the filing organization file **Form 1120-POL** for this year? ☐ Yes ☐ No
- 5 Enter the names, addresses and employer identification number (EIN) of all section 527 political organizations to which the filing organization made payments For each organization listed, enter the amount paid from the filing organization's funds Also enter the amount of political contributions received that were promptly and directly delivered to a separate political organization, such as a separate segregated fund or a political action committee (PAC) If additional space is needed, provide information in Part IV

(a) Name	(b) Address	(c) EIN	(d) Amount paid from filing organization's funds If none, enter -0-	(e) Amount of political contributions received and promptly and directly delivered to a separate political organization If none, enter -0-
1				
2				
3				
4				
5				
6				

Part II-A Complete if the organization is exempt under section 501(c)(3) and filed Form 5768 (election under section 501(h)).

A Check ☐ if the filing organization belongs to an affiliated group (and list in Part IV each affiliated group member's name, address, EIN, expenses, and share of excess lobbying expenditures)

B Check ☐ if the filing organization checked box A and "limited control" provisions apply

Limits on Lobbying Expenditures
(The term "expenditures" means amounts paid or incurred.)**(a)** Filing
organization's
totals**(b)** Affiliated group
totals**1a** Total lobbying expenditures to influence public opinion (grass roots lobbying)

12,666

b Total lobbying expenditures to influence a legislative body (direct lobbying)

325,095

c Total lobbying expenditures (add lines 1a and 1b)

337,761

d Other exempt purpose expenditures

41,451,933

e Total exempt purpose expenditures (add lines 1c and 1d)

41,789,694

f Lobbying nontaxable amount Enter the amount from the following table in both columns

1,000,000

If the amount on line 1e, column (a) or (b) is:	The lobbying nontaxable amount is:
Not over \$500,000	20% of the amount on line 1e
Over \$500,000 but not over \$1,000,000	\$100,000 plus 15% of the excess over \$500,000
Over \$1,000,000 but not over \$1,500,000	\$175,000 plus 10% of the excess over \$1,000,000
Over \$1,500,000 but not over \$17,000,000	\$225,000 plus 5% of the excess over \$1,500,000
Over \$17,000,000	\$1,000,000

g Grassroots nontaxable amount (enter 25% of line 1f)

250,000

h Subtract line 1g from line 1a. If zero or less, enter -0-

0

i Subtract line 1f from line 1c. If zero or less, enter -0-

0

j If there is an amount other than zero on either line 1h or line 1i, did the organization file Form 4720 reporting section 4911 tax for this year?

☐ **Yes** ☐ **No****4-Year Averaging Period Under Section 501(h)**

(Some organizations that made a section 501(h) election do not have to complete all of the five columns below. See the separate instructions for lines 2a through 2f.)

Lobbying Expenditures During 4-Year Averaging Period

Calendar year (or fiscal year beginning in)	(a) 2016	(b) 2017	(c) 2018	(d) 2019	(e) Total
2a Lobbying nontaxable amount				1,000,000	1,000,000
b Lobbying ceiling amount (150% of line 2a, column(e))					1,500,000
c Total lobbying expenditures				337,761	337,761
d Grassroots nontaxable amount				250,000	250,000
e Grassroots ceiling amount (150% of line 2d, column (e))					375,000
f Grassroots lobbying expenditures				12,666	12,666

Part II-B Complete if the organization is exempt under section 501(c)(3) and has NOT filed Form 5768 (election under section 501(h)).

For each "Yes" response on lines 1a through 1i below, provide in Part IV a detailed description of the lobbying activity

		(a)		(b)
		Yes	No	Amount
1	During the year, did the filing organization attempt to influence foreign, national, state or local legislation, including any attempt to influence public opinion on a legislative matter or referendum, through the use of			
a	Volunteers?			
b	Paid staff or management (include compensation in expenses reported on lines 1c through 1i)?			
c	Media advertisements?			
d	Mailings to members, legislators, or the public?			
e	Publications, or published or broadcast statements?			
f	Grants to other organizations for lobbying purposes?			
g	Direct contact with legislators, their staffs, government officials, or a legislative body?			
h	Rallies, demonstrations, seminars, conventions, speeches, lectures, or any similar means?			
i	Other activities?			
j	Total. Add lines 1c through 1i			
2a	Did the activities in line 1 cause the organization to be not described in section 501(c)(3)?			
b	If "Yes," enter the amount of any tax incurred under section 4912			
c	If "Yes," enter the amount of any tax incurred by organization managers under section 4912			
d	If the filing organization incurred a section 4912 tax, did it file Form 4720 for this year?			

Part III-A Complete if the organization is exempt under section 501(c)(4), section 501(c)(5), or section 501(c)(6).

	Yes	No
1 Were substantially all (90% or more) dues received nondeductible by members?	1	
2 Did the organization make only in-house lobbying expenditures of \$2,000 or less?	2	
3 Did the organization agree to carry over lobbying and political expenditures from the prior year?	3	

Part III-B Complete if the organization is exempt under section 501(c)(4), section 501(c)(5), or section 501(c)(6) and if either (a) BOTH Part III-A, lines 1 and 2, are answered "No" OR (b) Part III-A, line 3, is answered "Yes."

1 Dues, assessments and similar amounts from members	1	
2 Section 162(e) nondeductible lobbying and political expenditures (do not include amounts of political expenses for which the section 527(f) tax was paid).		
a Current year	2a	
b Carryover from last year	2b	
c Total	2c	
3 Aggregate amount reported in section 6033(e)(1)(A) notices of nondeductible section 162(e) dues	3	
4 If notices were sent and the amount on line 2c exceeds the amount on line 3, what portion of the excess does the organization agree to carryover to the reasonable estimate of nondeductible lobbying and political expenditure next year?	4	
5 Taxable amount of lobbying and political expenditures (see instructions)	5	

Part IV Supplemental Information

Provide the descriptions required for Part I-A, line 1, Part I-B, line 4, Part I-C, line 5, Part II-A (affiliated group list), Part II-A, lines 1 and 2 (see instructions), and Part II-B, line 1. Also, complete this part for any additional information.

Return Reference	Explanation

efile GRAPHIC print - DO NOT PROCESS

As Filed Data -

DLN: 93493217007180

SCHEDULE D
(Form 990)

Department of the Treasury
Internal Revenue Service

Supplemental Financial Statements

► Complete if the organization answered "Yes," on Form 990, Part IV, line 6, 7, 8, 9, 10, 11a, 11b, 11c, 11d, 11e, 11f, 12a, or 12b.
► Attach to Form 990.
► Go to www.irs.gov/Form990 for instructions and the latest information.

OMB No 1545-0047

2019

Open to Public Inspection

Name of the organization
NATIONAL ORGANIZATION FOR RARE DISORDERS INC

Employer identification number
13-3223946

Part I

Organizations Maintaining Donor Advised Funds or Other Similar Funds or Accounts.
Complete if the organization answered "Yes" on Form 990, Part IV, line 6.

1

Total number at end of year

2

Aggregate value of contributions to (during year)

3

Aggregate value of grants from (during year)

4

Aggregate value at end of year

(a) Donor advised funds

(b) Funds and other accounts

5

Did the organization inform all donors and donor advisors in writing that the assets held in donor advised funds are the organization's property, subject to the organization's exclusive legal control?

☐ Yes

☐ No

6

Did the organization inform all grantees, donors, and donor advisors in writing that grant funds can be used only for charitable purposes and not for the benefit of the donor or donor advisor, or for any other purpose conferring impermissible private benefit?

☐ Yes

☐ No

Part II

Conservation Easements.
Complete if the organization answered "Yes" on Form 990, Part IV, line 7.

1

Purpose(s) of conservation easements held by the organization (check all that apply)

☐ Preservation of land for public use (e g , recreation or education)

☐ Preservation of an historically important land area

☐ Protection of natural habitat

☐ Preservation of a certified historic structure

☐ Preservation of open space

2

Complete lines 2a through 2d if the organization held a qualified conservation contribution in the form of a conservation easement on the last day of the tax year

2a

Total number of conservation easements

2b

Total acreage restricted by conservation easements

2c

Number of conservation easements on a certified historic structure included in (a)

2d

Number of conservation easements included in (c) acquired after 7/25/06, and not on a historic structure listed in the National Register

3

Number of conservation easements modified, transferred, released, extinguished, or terminated by the organization during the tax year ►

4

Number of states where property subject to conservation easement is located ►

5

Does the organization have a written policy regarding the periodic monitoring, inspection, handling of violations, and enforcement of the conservation easements it holds?

☐ Yes

☐ No

6

Staff and volunteer hours devoted to monitoring, inspecting, handling of violations, and enforcing conservation easements during the year ►

7

Amount of expenses incurred in monitoring, inspecting, handling of violations, and enforcing conservation easements during the year ► \$

8

Does each conservation easement reported on line 2(d) above satisfy the requirements of section 170(h)(4)(B)(i) and section 170(h)(4)(B)(ii)?

☐ Yes

☐ No

9

In Part XIII, describe how the organization reports conservation easements in its revenue and expense statement, and balance sheet, and include, if applicable, the text of the footnote to the organization's financial statements that describes the organization's accounting for conservation easements

Part III

Organizations Maintaining Collections of Art, Historical Treasures, or Other Similar Assets.
Complete if the organization answered "Yes" on Form 990, Part IV, line 8.

1a

If the organization elected, as permitted under SFAS 116 (ASC 958), not to report in its revenue statement and balance sheet works of art, historical treasures, or other similar assets held for public exhibition, education, or research in furtherance of public service, provide, in Part XIII, the text of the footnote to its financial statements that describes these items

b

If the organization elected, as permitted under SFAS 116 (ASC 958), to report in its revenue statement and balance sheet works of art, historical treasures, or other similar assets held for public exhibition, education, or research in furtherance of public service, provide the following amounts relating to these items

(i) Revenue included on Form 990, Part VIII, line 1
(ii) Assets included in Form 990, Part X

2

If the organization received or held works of art, historical treasures, or other similar assets for financial gain, provide the following amounts required to be reported under SFAS 116 (ASC 958) relating to these items

a Revenue included on Form 990, Part VIII, line 1
b Assets included in Form 990, Part X

► \$

► \$

► \$

► \$

For Paperwork Reduction Act Notice, see the Instructions for Form 990.

Cat No 52283D

Schedule D (Form 990) 2019

Part III

Organizations Maintaining Collections of Art, Historical Treasures, or Other Similar Assets (continued)

3

Using the organization's acquisition, accession, and other records, check any of the following that are a significant use of its collection items (check all that apply)

a☐ Public exhibition

b☐ Scholarly research

c☐ Preservation for future generations

d☐ Loan or exchange programs

e☐ Other

4

Provide a description of the organization's collections and explain how they further the organization's exempt purpose in Part XIII

5

During the year, did the organization solicit or receive donations of art, historical treasures or other similar assets to be sold to raise funds rather than to be maintained as part of the organization's collection?

☐ Yes

☐ No

Part IV

Escrow and Custodial Arrangements.

Complete if the organization answered "Yes" on Form 990, Part IV, line 9, or reported an amount on Form 990, Part X, line 21.

1a

Is the organization an agent, trustee, custodian or other intermediary for contributions or other assets not included on Form 990, Part X?

☐ Yes

☐ No

b

If "Yes," explain the arrangement in Part XIII and complete the following table

c Beginning balance

d Additions during the year

e Distributions during the year

f Ending balance

	Amount
1c	
1d	
1e	
1f	

2a

Did the organization include an amount on Form 990, Part X, line 21, for escrow or custodial account liability? . . .

☐ Yes

☐ No

b

If "Yes," explain the arrangement in Part XIII Check here if the explanation has been provided in Part XIII

☐

Part V

Endowment Funds.

Complete if the organization answered "Yes" on Form 990, Part IV, line 10.

	(a) Current year	(b) Prior year	(c) Two years back	(d) Three years back	(e) Four years back
1a Beginning of year balance					
b Contributions					
c Net investment earnings, gains, and losses					
d Grants or scholarships					
e Other expenditures for facilities and programs					
f Administrative expenses					
g End of year balance					

2

Provide the estimated percentage of the current year end balance (line 1g, column (a)) held as

a Board designated or quasi-endowment ▶

b Permanent endowment ▶

c Temporarily restricted endowment ▶

The percentages on lines 2a, 2b, and 2c should equal 100%

3a

Are there endowment funds not in the possession of the organization that are held and administered for the organization by

(i) unrelated organizations

(ii) related organizations

	Yes	No
3a(i)		
3a(ii)		
3b		

b

If "Yes" on 3a(ii), are the related organizations listed as required on Schedule R?

4

Describe in Part XIII the intended uses of the organization's endowment funds

Part VI

Land, Buildings, and Equipment.

Complete if the organization answered "Yes" on Form 990, Part IV, line 11a. See Form 990, Part X, line 10.

Description of property	(a) Cost or other basis (investment)	(b) Cost or other basis (other)	(c) Accumulated depreciation	(d) Book value
1a Land		505,203		505,203
b Buildings		857,182	536,110	321,072
c Leasehold improvements				
d Equipment		31,731	22,144	9,587
e Other		2,866,185	2,214,286	651,899
Total. Add lines 1a through 1e (Column (d) must equal Form 990, Part X, column (B), line 10(c)) . . . ▶				1,487,761

Part VII

Investments—Other Securities.

Complete if the organization answered "Yes" on Form 990, Part IV, line 11b. See Form 990, Part X, line 12.

(a) Description of security or category (including name of security)	(b) Book value	(c) Method of valuation Cost or end-of-year market value
(1) Financial derivatives		
(2) Closely-held equity interests		
(3) Other _____		
(A)		
(B)		
(C)		
(D)		
(E)		
(F)		
(G)		
(H)		
Total. (Column (b) must equal Form 990, Part X, col (B) line 12) ▶		

Part VIII

Investments—Program Related.

Complete if the organization answered 'Yes' on Form 990, Part IV, line 11c. See Form 990, Part X, line 13.

(a) Description of investment	(b) Book value	(c) Method of valuation Cost or end-of-year market value
(1)		
(2)		
(3)		
(4)		
(5)		
(6)		
(7)		
(8)		
(9)		
Total. (Column (b) must equal Form 990, Part X, col (B) line 13) ▶		

Part IX

Other Assets.

Complete if the organization answered 'Yes' on Form 990, Part IV, line 11d. See Form 990, Part X, line 15

(a) Description	(b) Book value
(1)	
(2)	
(3)	
(4)	
(5)	
(6)	
(7)	
(8)	
(9)	
Total. (Column (b) must equal Form 990, Part X, col (B) line 15) ▶	

Part X

Other Liabilities.

Complete if the organization answered 'Yes' on Form 990, Part IV, line 11e or 11f. See Form 990, Part X, line 25.

1. (a) Description of liability	(b) Book value
(1) Federal income taxes	
(2)	
(3)	
(4)	
(5)	
(6)	
(7)	
(8)	
(9)	
Total. (Column (b) must equal Form 990, Part X, col (B) line 25) ▶	136,831

2. Liability for uncertain tax positions In Part XIII, provide the text of the footnote to the organization's financial statements that reports the organization's liability for uncertain tax positions under FIN 48 (ASC 740) Check here if the text of the footnote has been provided in Part XIII ☒

Schedule D (Form 990) 2019

Part XI Reconciliation of Revenue per Audited Financial Statements With Revenue per Return.

Complete if the organization answered 'Yes' on Form 990, Part IV, line 12a.

1	Total revenue, gains, and other support per audited financial statements	1	52,722,659
2	Amounts included on line 1 but not on Form 990, Part VIII, line 12		
a	Net unrealized gains (losses) on investments	2a	
b	Donated services and use of facilities	2b	85,000
c	Recoveries of prior year grants	2c	
d	Other (Describe in Part XIII)	2d	224,282
e	Add lines 2a through 2d	2e	309,282
3	Subtract line 2e from line 1	3	52,413,377
4	Amounts included on Form 990, Part VIII, line 12, but not on line 1		
a	Investment expenses not included on Form 990, Part VIII, line 7b	4a	
b	Other (Describe in Part XIII)	4b	
c	Add lines 4a and 4b	4c	0
5	Total revenue. Add lines 3 and 4c . (This must equal Form 990, Part I, line 12)	5	52,413,377

Part XII Reconciliation of Expenses per Audited Financial Statements With Expenses per Return.

Complete if the organization answered 'Yes' on Form 990, Part IV, line 12a.

1	Total expenses and losses per audited financial statements	1	42,098,976
2	Amounts included on line 1 but not on Form 990, Part IX, line 25		
a	Donated services and use of facilities	2a	85,000
b	Prior year adjustments	2b	
c	Other losses	2c	
d	Other (Describe in Part XIII)	2d	224,282
e	Add lines 2a through 2d	2e	309,282
3	Subtract line 2e from line 1	3	41,789,694
4	Amounts included on Form 990, Part IX, line 25, but not on line 1 :		
a	Investment expenses not included on Form 990, Part VIII, line 7b	4a	
b	Other (Describe in Part XIII)	4b	
c	Add lines 4a and 4b	4c	0
5	Total expenses. Add lines 3 and 4c . (This must equal Form 990, Part I, line 18)	5	41,789,694

Part XIII Supplemental Information

Provide the descriptions required for Part II, lines 3, 5, and 9, Part III, lines 1a and 4, Part IV, lines 1b and 2b, Part V, line 4, Part X, line 2, Part XI, lines 2d and 4b, and Part XII, lines 2d and 4b. Also complete this part to provide any additional information.

Return Reference	Explanation
See Additional Data Table	

Part XIII Supplemental Information *(continued)*

Return Reference	Explanation

Additional Data

Software ID:
Software Version:
EIN: 13-3223946
Name: NATIONAL ORGANIZATION FOR RARE
DISORDERS INC

Supplemental Information

Return Reference	Explanation
PART X, LINE 2	NORD ACCOUNTS FOR UNCERTAINTY IN INCOME TAXES IN ACCORDANCE WITH ASC TOPIC, INCOME TAXES THIS STANDARD CLARIFIES THE ACCOUNTING FOR UNCERTAINTY IN TAX POSITIONS AND PRESCRIBES A R ECOGNITION THRESHOLD AND MEASUREMENT ATTRIBUTE FOR THE FINANCIAL STATEMENTS REGARDING A TA X POSITION TAKEN OR EXPECTED TO BE TAKEN IN A TAX RETURN NORD HAS DETERMINED THAT THERE A RE NO UNCERTAIN TAX POSITIONS WHICH QUALIFY FOR EITHER RECOGNITION OR DISCLOSURE IN THE FI NANCIAL STATEMENTS AT DECEMBER 31, 2019 NORD'S INFORMATION RETURNS ARE SUBJECT TO EXAMINA TION BY THE FEDERAL AND STATE JURISDICTIONS

Supplemental Information	
Return Reference	Explanation
PART XI, LINE 2D - OTHER ADJUSTMENTS	FUNDRAISING EXPENSES 224,282

Supplemental Information	
Return Reference	Explanation
PART XII, LINE 2D - OTHER ADJUSTMENTS	FUNDRAISING EXPENSES 224,282

SCHEDULE F
(Form 990)

Department of the Treasury
Internal Revenue Service

Statement of Activities Outside the United States

► Complete if the organization answered "Yes" to Form 990, Part IV, line 14b, 15, or 16.
► Attach to Form 990.
► Go to www.irs.gov/Form990 for instructions and the latest information.

OMB No 1545-0047

2019

Open to Public Inspection

Name of the organization
NATIONAL ORGANIZATION FOR RARE
DISORDERS INC

Employer identification number
13-3223946

Part I

General Information on Activities Outside the United States. Complete if the organization answered "Yes" on Form 990, Part IV, line 14b.

1

For grantmakers. Does the organization maintain records to substantiate the amount of its grants and other assistance, the grantees' eligibility for the grants or assistance, and the selection criteria used to award the grants or assistance?

☐ Yes ☒ No

2

For grantmakers. Describe in Part V the organization's procedures for monitoring the use of its grants and other assistance outside the United States

3

Activites per Region (The following Part I, line 3 table can be duplicated if additional space is needed)

(a) Region	(b) Number of offices in the region	(c) Number of employees, agents, and independent contractors in the region	(d) Activities conducted in region (by type) (such as, fundraising, program services, investments, grants to recipients located in the region)	(e) If activity listed in (d) is a program service, describe specific type of service(s) in the region	(f) Total expenditures for and investments in the region
3a Sub-total	0	0			0
b Total from continuation sheets to Part I	0	0			0
c Totals (add lines 3a and 3b)	0	0			0

Part II Grants and Other Assistance to Organizations or Entities Outside the United States. Complete if the organization answered "Yes" on Form 990, Part IV, line 15, for any recipient who received more than \$5,000. Part II can be duplicated if additional space is needed.

1	(a) Name of organization	(b) IRS code section and EIN (if applicable)	(c) Region	(d) Purpose of grant	(e) Amount of cash grant	(f) Manner of cash disbursement	(g) Amount of noncash assistance	(h) Description of noncash assistance	(i) Method of valuation (book, FMV, appraisal, other)
			NORTH AMERICA	RESEARCH GRANT	25,000				BOOK
			EUROPE (INCLUDING ICELAND & GREENLAND)	RESEARCH GRANT	15,000				BOOK

- 2 Enter total number of recipient organizations listed above that are recognized as charities by the foreign country, recognized as tax-exempt by the IRS, or for which the grantee or counsel has provided a section 501(c)(3) equivalency letter **2**
- 3 Enter total number of other organizations or entities **0**

Part III	Grants and Other Assistance to Individuals Outside the United States. Complete if the organization answered "Yes" on Form 990, Part IV, line 16.
-----------------	---

Part III can be duplicated if additional space is needed.

[illegible]

Part IV Foreign Forms

- 1 Was the organization a U S transferor of property to a foreign corporation during the tax year? *If "Yes," the organization may be required to file Form 926, Return by a U S Transferor of Property to a Foreign Corporation (see Instructions for Form 926)* ☐ Yes ☒ No
- 2 Did the organization have an interest in a foreign trust during the tax year? *If "Yes," the organization may be required to separately file Form 3520, Annual Return to Report Transactions with Foreign Trusts and Receipt of Certain Foreign Gifts, and/or Form 3520-A, Annual Information Return of Foreign Trust With a U S Owner (see Instructions for Forms 3520 and 3520-A, don't file with Form 990)* ☐ Yes ☒ No
- 3 Did the organization have an ownership interest in a foreign corporation during the tax year? *If "Yes," the organization may be required to file Form 5471, Information Return of U S Persons with Respect to Certain Foreign Corporations (see Instructions for Form 5471)* ☐ Yes ☒ No
- 4 Was the organization a direct or indirect shareholder of a passive foreign investment company or a qualified electing fund during the tax year? *If "Yes," the organization may be required to file Form 8621, Information Return by a Shareholder of a Passive Foreign Investment Company or Qualified Electing Fund (see Instructions for Form 8621)* ☐ Yes ☒ No
- 5 Did the organization have an ownership interest in a foreign partnership during the tax year? *If "Yes," the organization may be required to file Form 8865, Return of U S Persons with Respect to Certain Foreign Partnerships (see Instructions for Form 8865)* ☐ Yes ☒ No
- 6 Did the organization have any operations in or related to any boycotting countries during the tax year? *If "Yes," the organization may be required to separately file Form 5713, International Boycott Report (see Instructions for Form 5713, don't file with Form 990)* ☐ Yes ☒ No

Part V

Supplemental Information

Provide the information required by Part I, line 2 (monitoring of funds); Part I, line 3, column (f) (accounting method; amounts of investments vs. expenditures per region); Part II, line 1 (accounting method); Part III (accounting method); and Part III, column (c) (estimated number of recipients), as applicable. Also complete this part to provide any additional information. See instructions.

990 Schedule F, Supplemental Information

Return Reference	Explanation
PART III ACCOUNTING METHOD	

Supplemental Information Regarding Fundraising or Gaming Activities

2019

Open to Public Inspection

Complete if the organization answered "Yes" on Form 990, Part IV, lines 17, 18, or 19, or if the organization entered more than \$15,000 on Form 990-EZ, line 6a
▶ Attach to Form 990 or Form 990-EZ.

▶ Go to www.irs.gov/Form990 for instructions and the latest information.

Employer identification number

13-3223946

1 Indicate whether the organization raised funds through any of the following activities. Check all that apply.

- 2a** Did the organization have a written or oral agreement with any individual (including officers, directors, trustees or key employees listed in Form 990, Part VII) or entity in connection with professional fundraising services? ☐ Yes ☐ No
- b** If "Yes," list the 10 highest paid individuals or entities (fundraisers) pursuant to agreements under which the fundraiser is to be compensated at least \$5,000 by the organization

3 List all states in which the organization is registered or licensed to solicit contributions or has been notified it is exempt from registration or licensing

Part II Fundraising Events. Complete if the organization answered "Yes" on Form 990, Part IV, line 18, or reported more than \$15,000 of fundraising event contributions and gross income on Form 990-EZ, lines 1 and 6b. List events with gross receipts greater than \$5,000.

Revenue		(a) Event #1	(b) Event #2	(c) Other events	(d) Total events
		ANNUAL GALA (event type)	(event type)	(total number)	(add col (a) through col (c))
	1 Gross receipts	5,500			5,500
	2 Less Contributions				
	3 Gross income (line 1 minus line 2)	5,500			5,500
Direct Expenses	4 Cash prizes				
	5 Noncash prizes				
	6 Rent/facility costs	19,375			19,375
	7 Food and beverages	104,429			104,429
	8 Entertainment	25,500			25,500
	9 Other direct expenses	74,978			74,978
	10 Direct expense summary Add lines 4 through 9 in column (d) ▶				224,282
11 Net income summary Subtract line 10 from line 3, column (d) ▶				-218,782	

Part III Gaming. Complete if the organization answered "Yes" on Form 990, Part IV, line 19, or reported more than \$15,000 on Form 990-EZ, line 6a.

Revenue		(a) Bingo	(b) Pull tabs/Instant bingo/progressive bingo	(c) Other gaming	(d) Total gaming (add col (a) through col (c))
	1 Gross revenue				
Direct Expenses	2 Cash prizes				
	3 Noncash prizes				
	4 Rent/facility costs				
	5 Other direct expenses				
	6 Volunteer labor	☐ Yes _____ % ☐ No	☐ Yes _____ % ☐ No	☐ Yes _____ % ☐ No	
7 Direct expense summary Add lines 2 through 5 in column (d) ▶					
8 Net gaming income summary Subtract line 7 from line 1, column (d) ▶					

9 Enter the state(s) in which the organization conducts gaming activities _____

a Is the organization licensed to conduct gaming activities in each of these states? ☐ Yes ☐ No

b If "No," explain _____

10a Were any of the organization's gaming licenses revoked, suspended or terminated during the tax year? ☐ Yes ☐ No

b If "Yes," explain _____

11 Does the organization conduct gaming activities with nonmembers?	☐ Yes ☐ No						
12 Is the organization a grantor, beneficiary or trustee of a trust or a member of a partnership or other entity formed to administer charitable gaming?	☐ Yes ☐ No						
13 Indicate the percentage of gaming activity conducted in							
a The organization's facility	<table border="1" style="display: inline-table; border-collapse: collapse;"> <tr> <td style="width: 10%;">13a</td> <td style="width: 70%;"></td> <td style="width: 20%; text-align: right;">%</td> </tr> <tr> <td>13b</td> <td></td> <td style="text-align: right;">%</td> </tr> </table>	13a		%	13b		%
13a		%					
13b		%					
b An outside facility							

14 Enter the name and address of the person who prepares the organization's gaming/special events books and records

Name ►

Address ►

15a Does the organization have a contract with a third party from whom the organization receives gaming revenue? ☐ **Yes** ☐ **No**

b If "Yes," enter the amount of gaming revenue received by the organization ► \$ _____ and the amount of gaming revenue retained by the third party ► \$ _____

c If "Yes," enter name and address of the third party

Name ►

Address ►

16 Gaming manager information

Name ►

Gaming manager compensation ► \$

Description of services provided ►

☐ Director/officer

☐ Employee

☐ Independent contractor

17 Mandatory distributions

a Is the organization required under state law to make charitable distributions from the gaming proceeds to retain the state gaming license? ☐ **Yes** ☐ **No**

b Enter the amount of distributions required under state law distributed to other exempt organizations or spent in the organization's own exempt activities during the tax year ► \$ _____

Part IV **Supplemental Information.** Provide the explanations required by Part I, line 2b, columns (iii) and (v); and Part III, lines 9, 9b, 10b, 15b, 15c, 16, and 17b, as applicable. Also provide any additional information. See instructions.

Return Reference

Explanation

Note: To capture the full content of this document, please select landscape mode (11" x 8.5") when printing.

Schedule I
(Form 990)

Department of the
Treasury
Internal Revenue Service

Name of the organization
NATIONAL ORGANIZATION FOR RARE
DISORDERS INC

Grants and Other Assistance to Organizations,
Governments and Individuals in the United States

Complete if the organization answered "Yes," on Form 990, Part IV, line 21 or 22.
▶ Attach to Form 990.
▶ Go to www.irs.gov/Form990 for the latest information.

OMB No 1545-0047

2019

Open to Public
Inspection

Employer identification number
13-3223946

Part I

General Information on Grants and Assistance

- 1 Does the organization maintain records to substantiate the amount of the grants or assistance, the grantees' eligibility for the grants or assistance, and the selection criteria used to award the grants or assistance?

☒ Yes ☐ No
- 2 Describe in Part IV the organization's procedures for monitoring the use of grant funds in the United States

Part II

Grants and Other Assistance to Domestic Organizations and Domestic Governments. Complete if the organization answered "Yes" on Form 990, Part IV, line 21, for any recipient that received more than \$5,000. Part II can be duplicated if additional space is needed

(a) Name and address of organization or government	(b) EIN	(c) IRC section (if applicable)	(d) Amount of cash grant	(e) Amount of non-cash assistance	(f) Method of valuation (book, FMV, appraisal, other)	(g) Description of noncash assistance	(h) Purpose of grant or assistance
(1) See Additional Data							
(2)							
(3)							
(4)							
(5)							
(6)							
(7)							
(8)							
(9)							
(10)							
(11)							
(12)							

2 Enter total number of section 501(c)(3) and government organizations listed in the line 1 table 9

3 Enter total number of other organizations listed in the line 1 table 0

Part III **Grants and Other Assistance to Domestic Individuals.** Complete if the organization answered "Yes" on Form 990, Part IV, line 22

Part III can be duplicated if additional space is needed

(a) Type of grant or assistance	(b) Number of recipients	(c) Amount of cash grant	(d) Amount of noncash assistance	(e) Method of valuation (book, FMV, appraisal, other)	(f) Description of noncash assistance
(1) PATIENT ASSISTANCE PROGRAMS	8231	30,812,906		BOOK	
(2)					
(3)					
(4)					
(5)					
(6)					
(7)					

Part IV **Supplemental Information.** Provide the information required in Part I, line 2; Part III, column (b); and any other additional information.

Return Reference	Explanation
PART I, LINE 2	ANY GRANTS AND SUPPORT GIVEN ARE CLOSELY MONITORED VIA REVIEW OF BACKUP DOCUMENTATION AND PROOF OF EXPENSE

Additional Data

Software ID:
Software Version:
EIN: 13-3223946
Name: NATIONAL ORGANIZATION FOR RARE
DISORDERS INC

Form 990, Schedule I, Part II, Grants and Other Assistance to Domestic Organizations and Domestic Governments.

(a) Name and address of organization or government	(b) EIN	(c) IRC section if applicable	(d) Amount of cash grant	(e) Amount of non-cash assistance	(f) Method of valuation (book, FMV, appraisal, other)	(g) Description of non-cash assistance	(h) Purpose of grant or assistance
BAYLOR COLLEGE OF MEDICINE 1 BAYLOR PLAZA HOUSTON, TX 77030	74-1613878		25,000		BOOK		RESEARCH GRANT
FOX CHASE CANCER CENTER 333 COTTMAN AVENUE PHILADELPHIA, PA 19111	23-2003072		15,000		BOOK		RESEARCH GRANT

Form 990, Schedule I, Part II, Grants and Other Assistance to Domestic Organizations and Domestic Governments.							
(a) Name and address of organization or government	(b) EIN	(c) IRC section if applicable	(d) Amount of cash grant	(e) Amount of non-cash assistance	(f) Method of valuation (book, FMV, appraisal, other)	(g) Description of non-cash assistance	(h) Purpose of grant or assistance
JOHNS HOPKINS UNIVERSITY 3901 KESWICK ROAD SUITE N4327B BALTIMORE, MD 21211	83-1496989		55,000		BOOK		RESEARCH GRANT
UNIVERSITY OF FLORIDA 3410 PALM BEACH BLVD FT MYERS, FL 33916	45-3450561		14,733		BOOK		RESEARCH GRANT

Form 990, Schedule I, Part II, Grants and Other Assistance to Domestic Organizations and Domestic Governments.							
(a) Name and address of organization or government	(b) EIN	(c) IRC section if applicable	(d) Amount of cash grant	(e) Amount of non-cash assistance	(f) Method of valuation (book, FMV, appraisal, other)	(g) Description of non-cash assistance	(h) Purpose of grant or assistance
WAKE FOREST UNIVERSITY HEALTH SCIENCES MEDICAL CENTER BLVD WINSTONSALEM, NC 27157	22-3849199		25,000		BOOK		RESEARCH GRANT
DUKE UNIVERSITY 316 TEER BUILDING BOX 90271 DURHAM, NC 27708	56-0532129		25,000		BOOK		RESEARCH GRANT

Form 990, Schedule I, Part II, Grants and Other Assistance to Domestic Organizations and Domestic Governments.							
(a) Name and address of organization or government	(b) EIN	(c) IRC section if applicable	(d) Amount of cash grant	(e) Amount of non-cash assistance	(f) Method of valuation (book, FMV, appraisal, other)	(g) Description of non-cash assistance	(h) Purpose of grant or assistance
UNIVERSITY OF PITTSBURGH 3959 FIFTH AVENUE PITTSBURG, PA 15213	25-0965591		22,500		BOOK		RESEARCH GRANT
BRIGHAM & WOMENS HOSPITAL 399 REVOLUTION DRIVE NO 645 SOMERVILLE, MA 02145	04-2312909		25,000		BOOK		RESEARCH GRANT

Form 990, Schedule I, Part II, Grants and Other Assistance to Domestic Organizations and Domestic Governments.

[illegible]

Schedule J (Form 990)	Compensation Information For certain Officers, Directors, Trustees, Key Employees, and Highest Compensated Employees ▶ Complete if the organization answered "Yes" on Form 990, Part IV, line 23. ▶ Attach to Form 990. ▶ Go to <u>www.irs.gov/Form990</u> for instructions and the latest information.	OMB No 1545-0047 2019 Open to Public Inspection
	Department of the Treasury Internal Revenue Service	
	Name of the organization NATIONAL ORGANIZATION FOR RARE DISORDERS INC	Employer identification number 13-3223946

Part I Questions Regarding Compensation		Yes	No
1a Check the appropriate box(es) if the organization provided any of the following to or for a person listed on Form 990, Part VII, Section A, line 1a Complete Part III to provide any relevant information regarding these items			
☐ First-class or charter travel ☐ Travel for companions ☐ Tax indemnification and gross-up payments ☐ Discretionary spending account ☐ Housing allowance or residence for personal use ☐ Payments for business use of personal residence ☐ Health or social club dues or initiation fees ☐ Personal services (e g , maid, chauffeur, chef)			
b If any of the boxes on Line 1a are checked, did the organization follow a written policy regarding payment or reimbursement or provision of all of the expenses described above? If "No," complete Part III to explain	1b		
2 Did the organization require substantiation prior to reimbursing or allowing expenses incurred by all directors, trustees, officers, including the CEO/Executive Director, regarding the items checked on Line 1a?	2		
3 Indicate which, if any, of the following the filing organization used to establish the compensation of the organization's CEO/Executive Director Check all that apply Do not check any boxes for methods used by a related organization to establish compensation of the CEO/Executive Director, but explain in Part III			
☐ Compensation committee ☐ Independent compensation consultant ☐ Form 990 of other organizations ☒ Written employment contract ☒ Compensation survey or study ☒ Approval by the board or compensation committee			
4 During the year, did any person listed on Form 990, Part VII, Section A, line 1a, with respect to the filing organization or a related organization			
a Receive a severance payment or change-of-control payment?	4a		No
b Participate in, or receive payment from, a supplemental nonqualified retirement plan?	4b		No
c Participate in, or receive payment from, an equity-based compensation arrangement? If "Yes" to any of lines 4a-c, list the persons and provide the applicable amounts for each item in Part III	4c		No
Only 501(c)(3), 501(c)(4), and 501(c)(29) organizations must complete lines 5-9.			
5 For persons listed on Form 990, Part VII, Section A, line 1a, did the organization pay or accrue any compensation contingent on the revenues of			
a The organization?	5a		No
b Any related organization? If "Yes," on line 5a or 5b, describe in Part III	5b		No
6 For persons listed on Form 990, Part VII, Section A, line 1a, did the organization pay or accrue any compensation contingent on the net earnings of			
a The organization?	6a		No
b Any related organization? If "Yes," on line 6a or 6b, describe in Part III	6b		No
7 For persons listed on Form 990, Part VII, Section A, line 1a, did the organization provide any nonfixed payments not described in lines 5 and 6? If "Yes," describe in Part III	7		No
8 Were any amounts reported on Form 990, Part VII, paid or accrued pursuant to a contract that was subject to the initial contract exception described in Regulations section 53.4958-4(a)(3)? If "Yes," describe in Part III	8		No
9 If "Yes" on line 8, did the organization also follow the rebuttable presumption procedure described in Regulations section 53.4958-6(c)?	9		

For each individual whose compensation must be reported on Schedule J, report compensation from the organization on row (i) and from related organizations, described in the instructions, on row (ii). Do not list any individuals that are not listed on Form 990, Part VII.

Note. The sum of columns (B)(i)-(iii) for each listed individual must equal the total amount of Form 990, Part VII, Section A, line 1a, applicable column (D) and (E) amounts for that individual.

Schedule J (Form 990) 2019

Part III **Supplemental Information**

Provide the information, explanation, or descriptions required for Part I, lines 1a, 1b, 3, 4a, 4b, 4c, 5a, 5b, 6a, 6b, 7, and 8, and for Part II. Also complete this part for any additional information.

Return Reference	Explanation
PART I, LINE 3	THE BOARD OF DIRECTORS REVIEWS EXTERNAL SURVEYS, DOL, BLS, AND ACCOUNTEMP SURVEYS FOR DECISIONS ON THE EXECUTIVE DIRECTOR'S COMPENSATION. THERE IS ALSO A SALARY ADMINISTRATION PLAN THAT TAKES INTO CONSIDERATION GEOGRAPHIC SETTINGS, SKILLS, AND EDUCATION.

SCHEDULE M
(Form 990)

Department of the Treasury
Internal Revenue Service

Noncash Contributions

►Complete if the organizations answered "Yes" on Form 990, Part IV, lines 29 or 30.
► Attach to Form 990.
►Go to www.irs.gov/Form990 for the latest information.

OMB No 1545-0047

2019

Open to Public Inspection

Name of the organization
NATIONAL ORGANIZATION FOR RARE
DISORDERS INC

Employer identification number
13-3223946

Part I

Types of Property

	(a) Check if applicable	(b) Number of contributions or items contributed	(c) Noncash contribution amounts reported on Form 990, Part VIII, line 1g	(d) Method of determining noncash contribution amounts
1 Art—Works of art				
2 Art—Historical treasures . .				
3 Art—Fractional interests . .				
4 Books and publications . .				
5 Clothing and household goods				
6 Cars and other vehicles . . .				
7 Boats and planes				
8 Intellectual property				
9 Securities—Publicly traded .	X	4	118,421	FAIR VALUE
10 Securities—Closely held stock .				
11 Securities—Partnership, LLC, or trust interests				
12 Securities—Miscellaneous . .				
13 Qualified conservation contribution—Historic structures				
14 Qualified conservation contribution—Other				
15 Real estate—Residential . .				
16 Real estate—Commercial . .				
17 Real estate—Other				
18 Collectibles				
19 Food inventory				
20 Drugs and medical supplies .				
21 Taxidermy				
22 Historical artifacts				
23 Scientific specimens				
24 Archeological artifacts				
25 Other ► (_____)				
26 Other ► (_____)				
27 Other ► (_____)				
28 Other ► (_____)				

29

Number of Forms 8283 received by the organization during the tax year for contributions for which the organization completed Form 8283, Part IV, Donee Acknowledgement

29

30a

During the year, did the organization receive by contribution any property reported in Part I, lines 1 through 28, that it must hold for at least three years from the date of the initial contribution, and which isn't required to be used for exempt purposes for the entire holding period?

Yes

No

30a

No

b If "Yes," describe the arrangement in Part II

31

Does the organization have a gift acceptance policy that requires the review of any nonstandard contributions?

Yes

No

31

No

32a

Does the organization hire or use third parties or related organizations to solicit, process, or sell noncash contributions?

Yes

No

32a

No

b If "Yes," describe in Part II

33

If the organization didn't report an amount in column (c) for a type of property for which column (a) is checked, describe in Part II

Yes

No

33

Part II **Supplemental Information.** Provide the information required by Part I, lines 30b, 32b, and 33, and whether the organization is reporting in Part I, column (b), the number of contributions, the number of items received, or a combination of both. Also complete this part for any additional information.

Return Reference	Explanation
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SCHEDULE O
(Form 990 or 990-EZ)

Department of the Treasury

Name of the organization

NATIONAL ORGANIZATION FOR RARE
DISORDERS INC**Supplemental Information to Form 990 or 990-EZ**Complete to provide information for responses to specific questions on
Form 990 or 990-EZ or to provide any additional information.

▶ Attach to Form 990 or 990-EZ.

▶ Go to www.irs.gov/Form990 for the latest information.

OMB No 1545-0047

2019**Open to Public
Inspection****Employer identification number**

13-3223946

990 Schedule O, Supplemental Information

Return Reference	Explanation
FORM 990, PART VI, SECTION B, LINE 11B	THE 990 IS REVIEWED BY THE VP OF FINANCE, CEO, FINANCE COMMITTEE, AND AUDIT COMMITTEE PRIOR TO FILING THE 990 IS PROVIDED TO ALL MEMBERS OF THE BOARD OF DIRECTORS FOR REVIEW PRIOR TO BEING FILED

990 Schedule O, Supplemental Information

Return Reference	Explanation
FORM 990, PART VI, SECTION B, LINE 12C	THE BOARD OF DIRECTORS ARE REQUIRED TO COMPLETE AN ANNUAL REVIEW OF THE ORGANIZATION'S CONFLICT OF INTEREST POLICY THE MEMBERS OF THE BOARD ARE ANNUALLY REQUIRED TO REPORT IF THEY HAVE OR DO NOT HAVE ANY KNOWN CONFLICTS OF INTEREST THE EXECUTIVE COMMITTEE IS ALSO REQUIRED TO ANNUALLY SIGN OFF AS TO ANY KNOWN CONFLICTS THAT EXIST

990 Schedule O, Supplemental Information

Return Reference	Explanation
FORM 990, PART VI, SECTION B, LINE 15	THE BOARD OF DIRECTORS REVIEWS EXTERNAL MARKET SURVEYS, DOL, BLS, AND ACCOUNTEMP SURVEYS F OR DECISIONS ON THE EXECUTIVE DIRECTOR COMPENSATION THERE IS ALSO A SALARY ADMINISTRATION PLAN THAT TAKES INTO CONSIDERATION GEOGRAPHIC SETTINGS, SKILLS, AND EDUCATION

990 Schedule O, Supplemental Information

Return Reference	Explanation
FORM 990, PART VI, SECTION C, LINE 19	GOVERNING DOCUMENTS ARE MADE AVAILABLE UPON REQUEST

990 Schedule O, Supplemental Information

Return Reference	Explanation
FORM 990, PART XII, LINE 2C	THE BOARD OF DIRECTORS ASSUMES RESPONSIBILITY FOR OVERSIGHT OF THE AUDIT OF ITS FINANCIAL STATEMENTS AND SELECTION OF AN INDEPENDENT ACCOUNTANT